

REPORT OF THE SELECT COMMITTEE ON MEDICAL ETHICS

VOLUME I—REPORT

Ordered to be printed 31 January 1994

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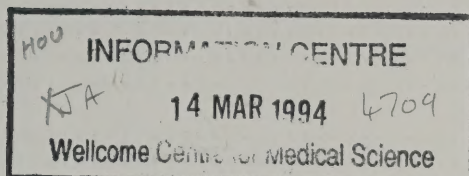
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REPORT

31 January 1994

By the Select Committee appointed to consider the ethical, legal and clinical implications of a person's right to withhold consent to life-prolonging treatment, and the position of persons who are no longer able to give or withhold consent;

and to consider whether and in what circumstances actions that have as their intention or a likely consequence the shortening of another person's life may be justified on the grounds that they accord with that person's wishes or with that person's best interests;

and in all the foregoing considerations to pay regard to the likely effects of changes in law or medical practice on society as a whole.

ORDERED TO REPORT

PART 1 INTRODUCTION

BACKGROUND

1. Decisions about medical treatment and the end of life are more complicated now than they have ever been. Such decisions are now more frequent, more difficult and more widely debated than in the past.

2. Perhaps the single most important reason for this is the advances in medicine in recent years, and particularly the application of medical technology. As a result patients live longer, where in the past they would have died at an earlier stage of their illnesses. Conditions which not so long ago would have resulted in certain, and fairly swift, death can now be treated and, if not cured, at least held at bay. For many this has resulted in a welcome prolongation of meaningful life, and avoidance of suffering. But for others the poor quality of life which results may raise the question whether treatment will be a benefit or a burden to the patient.

3. Another reason is demographic. As medicine has overcome many life-threatening conditions, more and more of the population are surviving longer and facing the chronic, degenerative conditions which old age may bring. The social implications of this are enormous, since to care adequately for the resulting large numbers of sick and elderly patients is difficult and costly. For some, too, old age may entail a weariness of living, and a wish not to have life prolonged by medical means. Some people cannot accept that their lives could continue to have meaning and value if overtaken by serious illness, disability or dependence.

4. Another factor is the change in the relationship between doctor and patient. The increased importance attached to individual autonomy, or the freedom to make decisions for oneself, has meant that relationships between state and citizen, between doctor and patient, teacher and pupil, parent and child, have all become less paternalistic. Most individuals wish to take more responsibility for the course of their lives, and this applies equally to decisions about medical treatment. Whereas in the past decisions were often left to the doctor alone, decisions are usually now the result of consultation between the patient and the health-care team, with the patient's relatives generally playing a role as well.

5. For all these reasons, there has been wide debate about medical treatment and the end of life. As part of that debate the practice of euthanasia has been much discussed, and a range of bodies has considered the issue. In 1988 for example the British Medical Association (BMA) set up a working

party to review their guidance on euthanasia¹. The 1993 Stevens lecture at the Royal Society of Medicine, the Society's main annual event for lay people, was also on this subject. Campaigning by various interest groups has intensified.

6. The trial of Dr Nigel Cox in 1992, and his conviction for attempted murder after he administered a lethal dose to a suffering patient, prompted great controversy. Some people were concerned that Dr Cox had been prosecuted at all, since he had acted in accordance with the wishes of the patient and her family and with a merciful motive. Others were concerned that, although having broken the law and breached the ethical code of his profession, he received only a suspended sentence and was merely admonished by the General Medical Council (GMC)².

7. Different, but related and no less difficult, questions were raised by the case of Anthony Bland, a young man severely injured in the Hillsborough stadium disaster in 1989 and who survived for several years in a persistent vegetative state³ (pvs). The local health authority, with the support of his family, sought and received a declaration from the High Court, later confirmed by the Court of Appeal and the House of Lords, to the effect that it would be lawful for the artificial nutrition and hydration on which he depended to be discontinued. Some people welcomed the decision that Bland's body need no longer be kept alive, since they considered that all the functions which had made him an individual had been irretrievably lost. Others felt that nutrition and hydration are such basic elements of care that they should only be withdrawn when the patient is in the final stages of the dying process, and that their discontinuance in this case amounted to deliberate killing. This case too gave rise to much press comment⁴ and much public debate. Two of the Lords of Appeal in Ordinary who heard the appeal to the House of Lords called for Parliamentary consideration of the issues involved. Lord Browne-Wilkinson said it was "imperative that the moral, social and legal issues raised by this case should be considered by Parliament...If Parliament fails to act, then judge-made law will of necessity through a gradual and uncertain process provide a legal answer to each new question as it arises. But in my judgment that is not the best way to proceed"⁵.

8. Debate on these issues has by no means been confined to the United Kingdom. In Canada the Law Reform Commission has considered them⁶ and recently the case of Sue Rodriguez has received wide publicity⁷. In New Zealand the Medical Council has reported on pvs and the withdrawal of food and fluids⁸. In 1991 the European Parliament's Committee on the Environment, Public Health and Consumer Protection adopted a resolution in favour of voluntary euthanasia⁹.

9. In the United States of America, in a healthcare environment very different from our own, there have been several legal cases concerning the treatment of patients in pvs¹⁰. Legislation promoting advance directives has been adopted in many states. The activities of Jack Kervorkian, who has assisted the suicide of a number of women by means of his so-called "suicide machine" which administers various lethal drugs, have given rise to litigation and have been widely

¹ BMA, *The Euthanasia Report*, 1988.

² For press comment on the case see for example Sunday Times 20 September; Times 24 September; Spectator 26 September; Financial Times 3 October; Guardian 6 October; New Scientist 24 October; (all 1992).

³ For discussion of this condition see paragraph 156, and Appendix 4.

⁴ See for example Daily Telegraph, Guardian 5 February; The Lancet 13 February; The Tablet 13 March; (all 1993).

⁵ [1993] AC. 789.

⁶ Law Reform Commission of Canada, *Report on Euthanasia, Aiding Suicide and Cessation of Treatment*, 1983.

⁷ Sue Rodriguez, suffering from amyotrophic lateral sclerosis, sought a court order permitting her doctor to assist her suicide when the disease had advanced to such a degree that she no longer wished to live. She was unsuccessful in the lower courts and the Supreme Court dismissed her appeal by a majority judgment on 30 September 1993.

⁸ Report by the Bioethics Research Centre, University of Otago, February 1993.

⁹ DOC EN/RR/108939, PE 146.436/fin.

¹⁰ See for example *Re Quinlan* (1976) 355 A 2d 647, Supreme Court of New Jersey; *Cruzan v Harmon* (1988) 760 SW 2d 408, Supreme Court of Missouri; *Re Doe* (1992) 583 NE 2d 1263, Supreme Judicial Court of Massachusetts. See also the discussion at pp 192-3 of the evidence.

debated¹. He is now indicted and facing prosecution in the state of Michigan. In Washington State in 1991 a proposition in favour of physician aid-in-dying for terminally ill people was supported by 46 per cent of those who voted. A similar proposition in California a year later attracted a similar level of support but an attempt to legalise voluntary euthanasia failed².

10. In the Netherlands euthanasia, though still a crime under the Dutch Penal Code, has been openly practised for some time. Since the late 1970s legal precedents have been developed such that, providing specific guidelines are observed, a doctor practising euthanasia will not be prosecuted. Among other conditions, the guidelines require that euthanasia should be voluntary and the decision should be made with the concurrence of a second independent physician. After it has been carried out the act must be notified to the coroner and district attorney who decide whether or not to prosecute. A government commission in 1991 considered the operation of this system and its findings gave rise to much controversy³. In 1993 the Dutch parliament enacted provisions to formalise the guidelines and the notification procedure for voluntary euthanasia.

THE COMMITTEE'S ENQUIRY

11. It was against this background that the House decided to appoint a Select Committee to consider certain aspects of medical ethics. Our terms of reference address not only euthanasia but also a number of other difficult issues; where similar implications arise.

12. The first part of our terms of reference raises the issue of when it is appropriate to discontinue, or not to initiate, medical treatment⁴. Different considerations inevitably arise in the case of patients who are legally competent and of sound mind and in the case of those who are unable for whatever reason to express their wishes about treatment and are thus incapable of giving valid consent.

13. The second part raises the issue of euthanasia as commonly understood, meaning a deliberate intervention undertaken with the express intention of ending life. This presents the crucial question of whether deliberate killing can ever be justified by the wish of the person killed or by an intention to be merciful.

14. The final part of our terms of reference reminds us that we must consider these matters not only from the point of view of the interests of the individual, or of the medical and allied health professions, or indeed of any other specific group, but of society as a whole.

15. Our terms of reference embrace a wide spectrum of different medical conditions, yet it is the two extremes that come most often to mind when people discuss matters of life and death. At one end of the spectrum is the terminally-ill cancer patient, who is conscious and able to participate in decisions about treatment and for whom the priority is likely to be to achieve the best possible quality of life for the time remaining, by the relief of painful or distressing symptoms. At the other end of the spectrum is the pvs patient, who has no cognitive functions, is not dying, as far as we can tell suffers no pain, but on whom medical treatment appears to confer little if any benefit. In between these two examples lies a whole range of circumstances: the patient with advanced Alzheimer's disease whose relatives may suggest that continued life in such a condition is not what the patient would have wished; the patient with progressive multiple sclerosis who fears continuing to live in an increasingly disabled state; and many others.

16. After some preliminary consideration, we published a report⁵ which set out the issues which we felt our terms of reference required us to consider. These were—

¹ For a discussion of this case see p 204 of the evidence.

² For details of the two propositions see p 205 of the evidence.

³ Some of the commission's findings are summarised in paragraphs 121 and 122.

⁴ The expression "medical treatment" was not defined in our terms of reference, but its scope was much discussed by witnesses (see paragraphs 60 to 65).

⁵ Select Committee on Medical Ethics, Special Report Session 1992-93, HL Paper 67.

- the respective weight to be attached to the sometimes conflicting moral principles of the sanctity of life and the right to personal autonomy
- the extent of a doctor's duty of care to a patient
- the distinction between the withholding or withdrawal of medical treatment, and deliberate intervention to end life
- the different considerations arising in the case of patients who are legally competent and of sound mind, and of patients who are unable to express their own wishes about treatment
- the role of advance directives and proxy decision-makers
- the role of the courts in interpreting the law in the light of changing medical technology and practice
- the case for change in the existing law, and the nature and extent of such change
- the role of the hospice movement and advances in the care of the terminally ill
- the experience of other countries, in particular in Western Europe and the USA.

17. Our report also contained an open invitation for written evidence. We are most grateful to all those who responded to that invitation. The evidence which is printed is listed in the Table of Contents. We also received letters from many individuals, and their views are discussed in Appendix 2. We were greatly assisted at the beginning of our enquiry by the private advice of Professor Ian Kennedy, Director of the Centre of Medical Law and Ethics, King's College, London. We are grateful to him for his assistance.

18. Towards the end of our enquiry we made a visit to the Netherlands, to discuss experience there. We record our warm thanks to those who assisted us. An account of our visit is set out in Appendix 3.

TERMINOLOGY

19. In the course of our report we shall use a number of terms which are either not in common use, or are not always used consistently. In order to avoid misunderstanding we set out here the terms which we have adopted, and the meanings which we attach to them. However many of the concepts which we discuss are elusive. They do not readily lend themselves to precise definition and we recognise that our working definitions are unlikely to be accepted by all commentators.

20. The word **euthanasia** originally meant nothing more than gentle and easy death. In the context of our enquiry, however, we use it to mean a deliberate intervention undertaken with the express intention of ending a life to relieve intractable suffering.

21. The term **passive euthanasia** is often used to describe the withdrawal or withholding of some treatment necessary for the continuance of the patient's life. We consider this term to be misleading. There is plenty of scope for argument over the ethical equivalence of killing and letting die in certain circumstances. In the case of a patient terminally ill with cancer and expected to die very shortly, few people would think it obligatory that antibiotics should be used to treat pneumonia (unless necessary to relieve distressing symptoms), although the patient's life might thereby be prolonged for a few days. We therefore speak of **withdrawing or not initiating treatment** or of a **treatment-limiting decision**.

22. Some people also use the term passive euthanasia to describe the act of a doctor or other person who prescribes or administers pain-killers or other (eg sedative) drugs necessary for the relief of a patient's pain or severe distress, but in the knowledge that a probable consequence of the

prescription is a shortening of the patient's life. Again we think that this usage is incorrect. We speak instead of the **double effect**.

23. The state of mind of the person whose death might be brought about by an act of euthanasia, as we have defined it, is of course significant. **Voluntary euthanasia** occurs when the patient's death is brought about at his or her own request. **Non-voluntary euthanasia** may be used to describe the killing of a patient who does not have the capacity to understand what euthanasia means and cannot therefore form a request or withhold consent. **Involuntary euthanasia** has been used to describe the killing of a patient who is competent to request or consent to the act, but does not do so.

24. The need for society to offer special protection to those who are in any way disadvantaged makes the consideration of competence or capacity particularly important in these matters. We describe as **competent** those patients who are able to understand the available information about their conditions, to consider with medical advice the risks, benefits and burdens of different treatments or courses of action, and thus to make informed decisions. We describe as **incompetent** those patients who are unable, whether permanently or temporarily, to make decisions about their medical care.

25. The group of incompetent patients covers a wide range of individuals with varying medical histories. Incompetence may be the result of mental illness or handicap, of disease or of accident. Patients may be conscious but unable to make or communicate a decision; or they may be unconscious. Many people who were formerly competent to make their own decisions about medical treatment become incompetent in the last stages of their lives as their capacity is impaired by, for example, advanced dementia or the effects of other illness.

26. **Assisted suicide** is the term we use when a competent patient has formed a desire to end his or her life but requires help to perform the act, perhaps because of physical disability. When the help requested is given by a doctor, the act is called **physician-assisted suicide**. A common form of assistance might be providing a lethal dose of a drug for the patient to swallow.

27. We use the term **advance directive** (in preference to the equally common **living will**) to describe a document executed while a patient is competent, concerning his or her preferences about medical treatment in the event of becoming incompetent. The document may specify the types of treatment which the patient would or would not find acceptable in certain circumstances.

28. We use the term **proxy decision-maker** to refer to someone who is appointed to make decisions on behalf of someone who is unable to make decisions for him or herself. A proxy decision-maker may be nominated in advance by the patient while competent, or (as is common in the United States of America) may be appointed by the court.

29. In the case of an incompetent patient, decisions about medical treatment may be made by a doctor in the patient's **best interests**. This is a difficult term to define, since it is used by different people to mean different things in different circumstances. The principle was articulated in the case of *In re F (Mental Patient: Sterilisation)*¹, where it was held that no-one could consent to medical treatment on behalf of an incompetent patient, but that a doctor could treat if it were in the patient's best interests to do so. In determining the patient's best interests, the doctor should act in accordance with a responsible and competent body of relevant professional opinion.

30. **Terminal illness** may be defined as an illness which is inevitably progressive, the effects of which cannot be reversed by treatment (although treatment may be successful in relieving symptoms temporarily) and which will inevitably result in death within a few months at most. It may be distinguished first from an **irreversible condition** (such as, for example, cerebral palsy or spina bifida) which is not progressive and does not necessarily lead to death and secondly from

¹ [1990] 2 A.C. 1-84.

chronic progressive disease (such as, for example, rheumatoid arthritis or multiple sclerosis) in which early death is not inevitable, though deterioration is. Definitions of **persistent vegetative state** are discussed in Appendix 4.

31. We use the expression **health-care team** to mean the doctors, nurses and other professionals involved in the care and medical treatment of the individual patient.

32. For a patient who is terminally ill, **palliative care** may be the most appropriate course which the health-care team can offer. The World Health Organisation has described palliative care as "a form of care that recognises that cure or long-term control is not possible; is concerned with the quality rather than quantity of life; and cloaks troublesome and distressing symptoms with treatments whose primary or sole aim is the highest possible measure of patient comfort"¹. The Department of Health said "palliative care is active total care provided to a patient when it is recognised that the illness is no longer curable. Palliative care concentrates on the quality of life and on alleviating pain and other distressing symptoms, and is intended neither to hasten nor postpone death" (P 2)².

STRUCTURE OF THE REPORT

33. Our report continues with a series of sections in which we consider the issues as presented by the evidence we have received and by the other material available to us. We end with an account of our conclusions and recommendations.

¹ World Health Organization, *Palliative cancer care*, 1989.

² For the definition given by the Association for Palliative Medicine, see P 190.

PART 2 THE EVIDENCE

THE VALUE OF LIFE

34. Belief in the special worth of human life is at the heart of civilised society. It is the fundamental value on which all others are based, and is the foundation of both law and medical practice. The intentional taking of human life is therefore the offence which society condemns most strongly.

35. Witnesses spoke in different ways about the value which human life holds. Some regarded it as a gift from God, and so to be cherished at all times. Others valued most highly its potential for human interaction and achievement, and set less store by the purely biological aspects of life. Nobody suggested that human life did not have its own intrinsic value.

36. The House of Bishops of the Church of England and the Catholic Bishops' Conference of England and Wales ("the Bishops") said "God himself has given to humankind the gift of life. As such, it is to be revered and cherished" (p 113)¹. The Board of Deputies of British Jews said that "the human being is possessed of a unique dignity since he is created in the spirit of Godliness" (p 15). LIFE argued that "to uphold and promote the utmost respect for human life regardless of sex, race, creed, age, prosperity, physical or mental achievement is fundamental to civilisation" (P 97)². The Linacre Centre for Health Care Ethics discussed at some length the sanctity of life, and argued that many secular theories of what gives human life its value are inadequate as foundations for dignity and justice (pp 156-8).

37. The BMA said that "doctors are more conscious than most of the enrichment brought to society by people who experience disability or suffering...life should be cherished and no individual should be seen as any less valuable because of physical or mental impairment" (P 27). On the other hand they do "not support the notion of the absolute sanctity of life or that purely organic functions must be prolonged indefinitely" and recognise that there are "circumstances in which it is appropriate that medical treatment should cease" (P 28). The Royal College of Nursing (RCN) said that "each person is unique and of infinite value" but that professionals should respect the varying beliefs of their patients "since care and treatment should be considered in terms of the patient's personal values" (P 71).

38. Professor Charles Fletcher³ expressed a different view of the importance of human life. "The main characteristics which distinguish human from animal life, and give it its special sanctity, are man's high intelligence and capacity for abstract thought" (p 109).

39. Professor Ronald Dworkin⁴ suggested that everybody accepted the idea of the "intrinsic value, the objective importance, the sanctity, if you will, of human life", but that that idea led different people to make different choices (Q 440). For him, the special value of life "resides in the capacity to respond to an environment, to respond to challenges, to give and receive affection in relationships and, of course, a mental life is at the centre of that" (Q 448).

CONSENT TO TREATMENT

40. Alongside the principle that human life is of special value, the principle is widely held that an individual should have some measure of autonomy to make choices about his or her life. Such autonomy has become important in relation to medical treatment, as the relationship between doctor and patient has changed to one of partnership. As the law stands, medical treatment may be given to competent adult patients only with their informed consent, unless in an emergency. This requirement entails the doctor explaining to the patient the treatment proposed, its attendant risks

¹ For similar views expressed by other witnesses see for example pp 51, 64, 93, 116, 124, 186, 195, 284.

² See also Q 252.

³ Professor Emeritus of Clinical Epidemiology, University of London.

⁴ Professor of Jurisprudence at Oxford and Professor of Law at New York University.

and potential benefits, and the patient making a decision on the basis of the information and advice given¹.

41. As a corollary of that, an adult patient who is competent, and fully informed of the consequences, has a right to refuse treatment, even if such refusal is likely to result in death². In 1985 Lord Scarman said that "a doctor who operates without the consent of the patient is...guilty of the civil wrong of trespass to the person; he is also guilty of the criminal offence of assault"³. In 1992 the Court of Appeal affirmed the right of the competent adult patient to refuse treatment, in *Re T*⁴.

42. The Department of Health emphasised this right very positively. "A patient who has the necessary mental capacity and has been properly informed of the nature of his condition and the implications of the treatment proposed is entitled to accept or decline that treatment as he sees fit...The patient's right to self-determination regarding the treatment he will accept is paramount" (P 2). The BMA said "ultimately the individual's right to self determination decides whether or not treatment can be given...the decisions of a competent patient regarding non-treatment must be respected" (P 27). Other witnesses also attached importance to the right of the patient to refuse treatment⁵.

43. Others, such as the Board of Deputies of British Jews, had a different view of refusal of treatment. They said "Anyone who can be healed and who chooses to refuse proven therapies also violates Jewish Law. Decisions to withhold medical treatment can be accepted if based upon the objective medical determination that the proposed treatment has no therapeutic value. But they are not acceptable if based upon the simple exercise of personal autonomy to refuse healing" (p 16). The Society for the Protection of Unborn Children (SPUC) made a similar point. "Even if there is an absolute legal right to refuse all medical treatments, there is no such absolute moral or ethical right...Where consent is refused simply in order to hasten death, it amounts to suicide and is unethical" (P 232)⁶.

44. Given the quite proper emphasis on competence as a prerequisite for a patient's decisions about treatment, some have suggested there is a danger that a decision contrary to a doctor's professional judgment might be taken as evidence of incompetence, and so the patient's right to refuse denied. The Alzheimer's Disease Society said that in their experience "doctors often...assume that a patient who disagrees with them is behaving irrationally and is thus incapable of giving informed consent" (p 6). The Royal College of Psychiatrists said that it was "important to distinguish between those who have degrees of difficulty with communication...and those who lack the mental capacity to consider choices competently" (p 219). The Department of Health made it clear that a patient's decision should be determinative provided it was "genuine, made with a full understanding of the consequences, and not influenced by others or clouded by mental disorder". Where the doctor doubted any of these points, a second medical opinion should be sought, and the matter discussed with other members of the health care team and with the patient's relatives and friends, who could cast light on whether the decision was in keeping with the patient's previous wishes (P 13)⁷. The Feminist Legal Research Unit at the University of Liverpool suggested that the decision about competence should be taken separately from the decision about treatment (p 104), to remove the danger of a patient being judged incompetent simply because he or she chose not to accept the doctor's advice about treatment.

¹ The Department of Health's NHS Management Executive issues guidance to health authorities on this issue, in the form of a circular entitled *A guide to consent for examination or treatment*. The BMA also gives detailed advice to doctors in the handbook *Medical Ethics Today: Its Practice and Philosophy*, 1993.

² For a clear account see the evidence of the Centre of Medical Law and Ethics, King's College, London (p 54).

³ *Sidaway v Bethlem Royal Hospital Governors* [1985] 1 All ER. 643.

⁴ *Adult: Refusal of Treatment* [1992] 3 WLR 782.

⁵ See for example PP 71, 140; pp 8, 25, 95, 216.

⁶ See also QQ 658,661.

⁷ The BMA also emphasised the importance of such steps (QQ 74, 75).

45. The BMA suggested that a too-ready acceptance of a patient's expressed view could also carry risks. "Even apparently clear patient requests for cessation of treatment sometimes stem from ambivalence or may be affected by an undiagnosed depressive illness which, if successfully treated, might affect the patient's attitude". They emphasised that respect for the patient's view should be "part of a genuine striving for partnership in decision-making between patient and doctor" (P 27)¹.

46. A number of witnesses who attached importance to the patient's right to refuse consent to treatment expressed concern about the High Court judgment which permitted a Caesarean section to be performed against the express wishes of the woman in question². The woman refused the operation on religious grounds, although she had been advised that both she and the fetus would die without it. In the event, the operation was performed, the woman survived but the child died. Sir Stephen Brown³ indicated that the case was heard and judgment given as a matter of urgency, at very short notice (Q 294).

47. The Royal College of Midwives said that the judgment "caused great concern for midwives" and that the situation required urgent clarification (p 216). The Centre of Medical Law and Ethics set out the difficulties to which the decision gave rise. They suggested that the decision—whether intended to save the woman's life, to protect the interests of the unborn child, or to assert "society's interest in preserving the baby's life where there is the potential to become a legal person"—was contrary to existing case law (p 56). The Feminist Legal Research Unit at the University of Liverpool also discussed what they saw as the inadequacies of the judgment, and its implications (pp 95-100).

48. In the case of children, parents or those having parental responsibility under the Children Act 1989 can consent to treatment if it is in the best interests of the child. Minors aged 16 and 17 are presumed to be competent to consent to treatment⁴ unless there is reason to suppose that they are not. Children under the age of 16 may consent to treatment if they have "sufficient understanding and intelligence...to understand fully what is proposed"⁵.

49. However the right of minors to refuse consent has not been upheld by the courts. In two cases the courts have given consent for treatment of a competent minor who had refused treatment⁶. The Feminist Legal Research Unit suggested that this denial of a right to refuse consent makes meaningless the right to give consent (p 104).

TREATMENT-LIMITING DECISIONS

50. A patient's refusal of consent to treatment is not the only circumstance in which a doctor may do less than all that medical technology makes possible, and our witnesses recognised that there comes a moment in the care of any patient when it is right for the doctor to refrain from further attempts to prolong life⁷. This was acknowledged in 1980 by the Roman Catholic Church: "The Church does not insist that a dying or seriously ill person should be kept alive by all possible means for as long as possible. The treatment should be proportionate to the therapeutic effect to be expected, and should not be disproportionately painful, intrusive, risky and costly in the circumstances"⁸. The Christian Medical Fellowship said "we see no requirement to give all possible treatments to all possible patients in all possible situations just because those treatments exist. It is precisely this sort of meddlesome medicine which does not recognise that the natural end is drawing near that has led to over-treatment of some patients...a time may come when

¹ See also Q 77.

² *In Re S (Adult: Refusal of Treatment)* [1992] 3 WLR 806.

³ President of the Family Division of the High Court of Justice.

⁴ Family Law Reform Act 1969.

⁵ *Gillick v. West Norfolk and Wisbech Area Health Authority and another* [1985] 3 All ER 402.

⁶ *Re R* [1991] 4 All ER 177 and *Re W* [1993] Fam. 64.

⁷ See for example pp 41, 44, 85, 93, 114, 128, 195, 263, 284; PP 235, 248.

⁸ Sacred Congregation of the Doctrine of the Faith, *Declaration on Euthanasia*, 1980.

interventionist treatment need not be started or continued, and the patient should be allowed to die" (p 64). The Board of Deputies of British Jews cited scriptural authorities in support of the view that it was proper not to prolong the process of dying (p 18).

51. The Linacre Centre rebutted suggestions that a belief in the sanctity of life entailed the obligation to prolong life at all costs. "The purpose of medicine is the restoration and maintenance of health (or of some approximation to health) or the palliation of symptoms...The prolongation of life has not traditionally been understood as an independent goal of medicine, without reference to the good of health. It has been considered a justifiable aim only in so far as a patient has had some continuing capacity for organic well-functioning sufficient to allow him to share in some of the goods of human life" (p 163).

52. The Linacre Centre identified two general reasons justifying a decision to limit treatment: "one is that a particular treatment is failing to achieve its therapeutic or palliative goal...the other is that it involves burdensome consequences which it is not reasonable to expect a patient to bear" (p 165)¹. They listed some of the burdens which treatment might impose, including pain, expense and conflict with other goals. They emphasised that a decision to limit treatment because of its burdensome consequences was a judgment on the treatment and not a judgment on the worth of the patient's continued existence. They pointed out that an incompetent patient's lack of understanding (for example that the pain will be temporary and that a benefit is anticipated) could make excessively burdensome a treatment which would not be so to a competent patient (p 166).

53. The Association for Palliative Medicine shared the view that to continue with futile or burdensome treatments was unnecessary, and could be irresponsible (Q 539).

54. Professor Bryan Jennett² described three circumstances in which decisions might be taken to limit treatment. One was where treatment would be futile, that is that it would not extend the life of the patient. The second was where treatment would prolong life for such a short period, or would cause such distress, that the burden was disproportionate to the benefit. The third was where the patient's expected quality of life was so poor that continued survival was not considered a benefit (p 118). He also set out four principles which should govern such decisions: beneficence, non-maleficence, respect for patient autonomy and justice in the distribution of resources (p 117)³. Professor Jennett drew our attention to surveys which suggest that a high proportion of deaths in hospital follow decisions to limit treatment: this is evidently a significant feature of medical practice (pp 117-118).

55. Some witnesses considered whether there was any ethical difference between not initiating life-prolonging treatment, and not continuing such treatment once begun. The BMA was clear that for practical purposes it was important that doctors should feel able to withdraw treatment which was not producing benefit for the patient. They could thus in an emergency situation initiate all potentially beneficial interventions, confident that the régime could be reviewed later (QQ 85-88). The British Geriatrics Society agreed: "it is very important that doctors should not be constrained in offering possibly beneficial treatment by the thought that they would not have the right to discontinue it if it were not benefiting the patient" (p 25).

56. Dr David Cook⁴, on the other hand, had some difficulty with the withdrawal of treatment, suggesting that active responsibility for outcome is greater in that event than if treatment is not begun. "It is much easier for all concerned if a decision is made not to begin a treatment" (P 170).

¹ The SPUC made a similar point (P 235).

² Emeritus Professor of Neurosurgery at the Institute of Neurological Sciences, Glasgow.

³ These principles were elaborated by the Appleton International Conference in *Developing Guidelines for Decisions to Forgo Life-Prolonging Medical Treatment* (Journal of Medical Ethics, September 1992 Volume 18: Supplement), to which Professor Jennett was a contributor. The Appleton Conference was a project which, over a period of five years, brought together doctors and other interested professionals from a range of countries to formulate guidelines for the withdrawal or withholding of treatment.

⁴ Fellow and Chaplain of Green College and Director of the Whitefield Institute, Oxford.

In oral evidence, however, he made clear that he did not object to the withdrawal of treatments which had been initiated in, for example, an emergency situation where prognosis was uncertain (Q 496).

57. During the course of our enquiry Lord Alport introduced a private member's bill¹ dealing with the termination of medical treatment. His intention was to clarify the law regarding the withdrawal of treatment once begun, to provide a framework within which both patients and health-care professionals could operate, without need for recourse to the courts (pp 3-5). He suggested that, partly as a result of medical advances and partly as a result of increased litigation, doctors needed a further safeguard in their treatment-limiting decisions (Q 728). Dr Peter Wilson² said that an established framework for the withdrawal of treatment would enable all members of the health-care team to agree on appropriate courses of action (Q 733). Lord Alport explained that another intention of his proposals was to avoid the trauma of court action for the families of incompetent patients (Q 725).

58. The Department of Health suggested that the Bill was flawed in at least one respect. One of its effects would be to limit the existing right of a competent patient to refuse treatment since a request for withdrawal of treatment would, under the provisions of the Bill, have to be made in writing and be certified by two medical practitioners (P 3). At present withdrawal of treatment may be requested orally at any time, and the patient's competence need only be certified where there is any doubt of it.

59. Subject to certain safeguards, Lord Alport's Bill would make legal the withdrawal of medication and of "any technical apparatus or therapy designed to provide ventilation, nutriment or fluid" (Clause 2). The Linacre Centre objected to the Bill because of its provision that nutrition and hydration could in certain circumstances be withdrawn (p 172). This issue is further discussed in paragraphs 62 to 66 below.

TREATMENT AND CARE

60. In discussing the appropriate management for particular patients, the BMA differentiated between treatment, which is dependent upon the agreement of the patient and upon some anticipated benefit for the patient, and care which must always be available even if treatment is discontinued (P 26). They emphasised that care is a continuing function whereas treatment is not (P 28). Other witnesses suggested that the distinction between treatment and care had been confused, and that this could lead to bad decision-making³.

61. A witness from LIFE talked about two phases of treatment for a patient with a life-threatening illness. She said "In the first phase the object and intention of treatment is cure...one may subject one's patients to unpleasant, painful or even themselves life-threatening treatments, provided that cure is the intended result". In the second phase, when it becomes apparent that cure is not possible, the priority becomes "comfort, the alleviation of symptoms, the production of a contented patient with a comfortable, pain-free life" (Q 230).

62. The distinction between treatment and care was crucial to judicial decision-making in the case of Anthony Bland. The question arose whether nutrition and hydration, when given by some invasive method (for example naso-gastric tube or intravenous feeding), should be regarded as a form of medical treatment which could, like other forms of medical treatment, be discontinued if they appeared to be of no benefit to the patient. The courts decided that they should be so regarded. The BMA accepted this decision (PP 51, 56).

¹ Termination of Medical Treatment Bill [H.L.], HL Bill 70, Session 1992-93.

² Consultant for the Elderly and Chronic Sick at the Essex County and Colchester General Hospitals, who attended to give evidence with Lord Alport.

³ See for example PP 108, 109; p 66; Q 464.

63. Some of our witnesses, however, disagreed. The RCN said that “to stop food and fluid is a different and more complex issue from the decision to stop other forms of medical intervention” (P 72). They said that nurses “see feeding somebody as very fundamental to our whole practice and that the withdrawal of feeding, in whatever form it is being given, can produce very strange conflicts for us” (Q 151). Dr David Lamb¹ also drew attention to the ethically symbolic role of the giving of nourishment (p 136).

64. Professor Scarisbrick of LIFE said “the courts did no service to society by saying that food and drink were a form of medical care” (Q 246). He said that to distinguish between feeding by mouth and feeding by other means was “tendentious because if an individual is in such a condition that the only way to feed him or her is via a tube or whatever, that is the normal way of feeding that person” (Q 229). He had no objection to “not striving heroically” to keep a patient alive when circumstances suggested that this was not the best course, but said “we are not dealing with high-tech medicine when we are talking about giving a fellow human being food and drink” (Q 238)². The Reformed Presbyterian Church of Ireland were unhappy about the decision since Bland was not terminally ill—they suggested that his death was caused by deprivation of food and water, and not by disease or injury (p 285). Healthcare Opposed to Euthanasia (HOPE) felt that the outcome of the Bland case indicated that “the law may have begun to accept the concept of intentional killing”, and suggested that there was a case for legislation “to reaffirm the previous prohibition of intentional killing, whether by act or omission” (P 112)⁴.

65. The BMA said that, as far as competent patients were concerned, they believed that “artificial feeding is a medical treatment which cannot be implemented contrary to the wishes of a patient who refuses consent. Such consent can be expressed through a competent advance directive” (P 38). Dr Gerard Corcoran⁵ made it clear that decisions about invasive methods of feeding for competent patients were made in the light of how burdensome the treatment would be in relation to the patient’s overall condition (Q 532).

66. Not surprisingly given its complexity and emotional connotations the subject of the withdrawal of nutrition and hydration has revealed a variety of different views within the Roman Catholic Church. In their joint statement the House of Bishops of the Church of England and the Catholic Bishops’ Conference of England and Wales said simply that the Bland case should not be used as an argument for change in the law, but that “every person’s needs and rights must be dealt with on a case to case basis” (P 114). Father Kevin Kelly, writing in *The Tablet*⁶, argued that withdrawing Bland’s artificial nutrition and hydration was not incompatible with the Roman Catholic tradition of medical ethics. He said “there is far more to life than simply staying alive” and that it was reasonable to believe that keeping alive through medical treatment a pvs patient was not in keeping with human dignity. The theologians Moira McQueen and J Leo Walsh defended the *Bland* judgment, since “the withdrawal of artificial nutrition and hydration in the type of cases under discussion is to be seen as an omission which is not an intending of death but a refusal to continue with inappropriate means of life preservation”⁷. On the other hand Bishop Christopher Budd and Archbishop Thomas Winning were reported to regard the decision as amounting to intentional killing by starvation⁸.

¹ Reader in Philosophy at the University of Manchester.

² See also P 98.

³ For similar views expressed by other witnesses see QQ 496, 668; PP 108, 149, 173, 234; pp 8, 18, 44, 75, 125, 167, 190, 197.

⁴ For similar views see also P 24; pp 174, 285.

⁵ Medical Director of St Gemma’s Hospice, and a representative of the Association for Palliative Medicine.

⁶ 13 March 1993.

⁷ *The Tablet* 19/26 December 1992.

⁸ *The Tablet* 28 November 1992.

67. In January 1994 the case of *Frenchay Healthcare NHS Trust v. S* again raised questions about nutrition and hydration. S, a pvs patient, had been fed by gastrostomy tube. When the tube was accidentally dislodged the trust responsible for his care sought authority from the courts not to replace it, on the grounds that this invasive procedure was not in the patient's best interests. The judgment of the High Court authorised the course proposed by the trust, and was upheld by the Court of Appeal.

KILLING AND LETTING DIE

68. The distinction between killing and letting die—or between act and omission—is one which has been much discussed by ethicists and philosophers, and by some of our witnesses¹. In law an omission to act is only significant where someone has a specific duty to act—for example a doctor who has a professional duty to care for a patient, or a parent who has a duty to care for a child—and fails to do so. Unlike many foreign legal codes, which contain “easy rescue” provisions, English law is such that, in the absence of a specific duty, a person commits no offence if he fails to save the life of another, although he could easily do so with no undue risk to himself.

69. The BMA suggested that although some boundaries might be perceived as arbitrary, there was nevertheless a need for recognised limits. They saw the distinction in law between killing and letting die as “a proper safeguard against the possibility of abuse” (P 28). Dr David Cook attached much importance to the distinction (PP 169, 170), as did Sir Robert Kilpatrick (Q 354)^{2 3}.

70. HOPE drew no distinction between act and omission. They suggested that “the concept of intention is crucial”: either an act or an omission would be wrong if its intention was solely to cause death⁴. They recognised that only the doctor would surely know what his or her true intention was, and so suggested that treatment decisions should be taken “after the widest discussion possible” (P 109). The Linacre Centre said “there is no morally significant *general* distinction to be made between killing and letting die...One may let a patient die for perfectly sound reasons...but one may also let a patient die for unacceptable reasons, including the absolutely unacceptable reason that one wants (however reluctantly) to hasten his death” (p 160). Dr Robert Twycross⁵ said that intention was an important guide to doctors in their everyday practice (Q 267).

71. Dr Fiona Randall⁶ suggested that the distinction between killing and letting die was a very necessary one. “If one says that withholding or withdrawing treatment is morally equivalent to killing a patient one will have to sue every doctor who does not insist that every patient dies in an intensive care unit with all possible tubes and contraptions. That is obviously contrary to commonsense” (Q 581).

72. Other witnesses regarded the distinction as questionable⁷. Professor Sheila McLean⁸ said “the distinction between act and omission, so often used to justify the difference between killing and letting die, is one which has long been widely regarded as philosophically disingenuous, and should in my opinion be so treated” (P 145). The United Kingdom Central Council for Nursing, Midwifery and Visiting (UKCC) said that “at times this distinction can appear nothing short of hypocritical” (P 139).

¹ See for example pp 22, 277-81.

² President of the General Medical Council, but who gave evidence to us in a personal capacity.

³ For a similar view see also Q 741.

⁴ For similar views see also Q 676; P 236; p 129.

⁵ MacMillan Clinical Reader in Palliative Medicine, University of Oxford.

⁶ Consultant in Palliative Medicine with the Christchurch Macmillan Service, and Wessex Regional Representative to the National Council for Hospice and Specialist Palliative Care Services.

⁷ See for example P 87; Q 218.

⁸ Director of the Institute of Law and Ethics in Medicine, University of Glasgow.

DOUBLE EFFECT

73. The common practice whereby a doctor prescribes sufficient drugs to control pain adequately, even though a probable consequence may be the shortening of the patient's life, was accepted by many witnesses as unexceptionable¹. The Bishops said "There is a proper and fundamental ethical distinction which cannot be ignored between that which is intended and that which is foreseen but unintended. For example, the administration of morphine is intended to relieve pain. The consequent shortening of life is foreseen but unintended. If safer drugs were available, they would be used" (p 114). Lord Jakobovits² said that "obligation to relieve pain is so overriding that, where medically indicated, analgesics should be administered even if they may shorten life, so long as this is not the intended purpose" (p 116). Sir Robert Kilpatrick believed that if relief of pain and suffering was not achieved with analgesic drugs, heavy sedation would be justifiable, even if this hastened the patient's end (QQ 369, 393)³.

74. The World Health Organisation⁴ sees no difficulty with double effect. "There is...no excuse for failure to use available methods to control pain adequately. If shortening of life results from the use of adequate doses of an analgesic drug, this is *not* the same as intentionally terminating life by overdose. Any hastening of death that is linked to adequate pain control measures simply means that the patient could no longer tolerate the therapy necessary for a bearable and dignified life".

75. The Crown Prosecution Service (CPS) said "the administering of pain-killing though life-shortening drugs to terminally ill patients is rendered lawful if the doctor is acting in the best interests of the patient, despite the fact that the patient will die as a consequence" (p 81). The Home Office pointed out that "such an act *may* be criminal" depending "both on the doctor's intention and on whether the doctor's actions can be said to have caused the patient's death" (P 16). They emphasised that "treatment given should be necessary to the relief of pain...The taking of action that has no pain-relieving qualities, and simply accelerates death, is not lawful" (Q 35). However they went on to say that "the existing law is, by and large, producing the right outcomes and not causing problems". Others also believed that the distinction between an action which caused death, and an action which might hasten death but which was undertaken for the relief of pain, was well understood by doctors and gave rise to little difficulty⁵.

76. Some witnesses did feel that double effect was a cause for concern. The UKCC said "to prohibit euthanasia...yet permit the use of narcotics to alleviate pain even at doses which will dramatically shorten life or even bring it to a close within a very short period, is no longer a sustainable position" (P 139). Mr Reg Pyne of the UKCC suggested that there was a widespread feeling among nurses that the present position was hypocritical (Q 436). The British Humanist Association were more forthright. "The doctrine of double effect seems to us a sophistry which is morally particularly damaging. Where there are two outcomes of a given action, one good and one bad, the action is justified only if the good outweighs the bad in moral significance; and the moral weights of the two outcomes depend on the outcomes and the overall context, and are quite independent of the doctor's self-described intentions. If a doctor knows, or should know, that a certain result will follow a certain action, and if his causing that result would be morally wrong, then that action is morally wrong. It is morally legitimate to give doses of pain-killer which are lethal (immediately or longer-term) only if it is morally legitimate to kill that patient (with immediate or delayed effect) in those circumstances" (p 30).

¹ See for example PP 2, 169; QQ 50, 239, 241; pp 41, 124, 184, 195.

² Former Chief Rabbi and author on medical ethics.

³ For a similar view see also Q 571.

⁴ In its report *Cancer pain relief and palliative care*, Geneva 1990.

⁵ See for example Q 122; P 169.

77. On the other hand Dr Derek Doyle¹ emphasised the unpredictable effects of opiates. "There is abundant evidence of people having been given inadvertently 20, 30 and even 100 times what has been prescribed. Whilst it can be a tragic error, the patient may wake up four hours later to say that it is the best sleep that he has had for some time" (Q 557). He also drew attention to new evidence that, far from being dangerous, opiates could have therapeutic as well as analgesic effects (Q 558).

78. Mr Pyne said that in his experience large doses of pain-killing drugs were often used with the intention of terminating life (Q 417)². Mr Ludovic Kennedy³ also suggested that many doctors used the legal option of giving pain-killing drugs in doses that might be expected to hasten death deliberately "in order to bring that person's life to an end". This he equated with euthanasia, and he suggested that since it was a common occurrence "it is a small step really to formalise it" (Q 328).

79. An understanding of intention is critical to the principle of double effect, yet intention is not infrequently confused with motive. Intention concerns the outcome desired as the result of an action. Motive concerns the reason for which that outcome is desired. At present, the Home Office told us, the law takes no account of motive in dealing with actions of deliberate killing, but does take notice of intention (Q 43)⁴. They said "A person who kills, with that as their clear intention and in their right mind, is guilty of murder even though they may have been motivated by a desire to end another's suffering or to give effect to their victim's clearly and honestly held wishes" (P 15).

ROLE OF THE LAW AND OF THE COURTS

80. The role of the criminal law in relation to the matters which we have considered was succinctly described by the Home Office. "The law should identify clearly actions that should properly be deemed criminal...The product of an adequate legal framework should be public confidence that the law protects both life and property...There can be no more important area in which the law's protection should be complete and transparent than where individuals' lives are at stake" (P 15). They warned us of the difficulties of attempting to legislate for medical decisions (QQ 40, 41).

81. In certain circumstances the civil courts are applied to for guidance in decisions about medical treatment. The Department of Health said that this should be the case where existing legal principles or professional protocols were insufficient to guide a doctor's decision (P 2). They said that the advantages of application to the courts were that a fully considered decision would be taken and doubt about the legality of the proposed action would be removed. Disadvantages were cost, delay and publicity (P 13). The Mental Health and Disability Sub-Committee of the Law Society noted that "going to court means that difficult, sensitive and painful decisions cease to be a private family matter and become the subject of an adversarial, and sometimes political battle...the adversarial nature of the court system can produce unnecessary divisiveness" (p 152).

82. The BMA said that "many decisions concerning treatment and non-treatment are of such importance to society, we believe that they should not be made solely between the individuals concerned but must be subject to various forms of review" (P 30). They urged that where such a review concerned a competent patient, the courts should give a full explanation of "the reasoning behind any apparent overruling of the patient's own opinion", noting that confusion had been created by a recent decision to overrule a pregnant woman's refusal of treatment (P 30).

¹ Consultant at St Columba's Hospice, and Vice-Chairman of the National Council for Hospice and Specialist Palliative Care Services.

² See also Professor Dworkin at Q 461.

³ Broadcaster and writer and a Vice-President of the VES.

⁴ Evidence as to motive may however be adduced in establishing intention.

83. Some witnesses recognised that recourse to the courts would inevitably be appropriate in certain difficult cases, but considered that the role of the courts should be kept to a minimum¹. Sir Stephen Brown said "it would seem appropriate, in the absence of any legal framework specifically laid down by Parliament, that such cases ought to be examined carefully, in public if possible...I feel the Family Division would be able to deal with these matters" (Q 285). He was confident that, despite being "heavily pressed", the Family Division could deal sufficiently swiftly with really urgent cases (Q 292). The Official Solicitor, who is usually invited to represent the interests of the incompetent patient in court (Q 285), said "My experience leads me to believe that all cases about withdrawal of life-prolonging treatment should be the subject of application to the civil courts for the time being at least. I am prepared to shoulder the burden of representing the mentally incompetent in such cases" (p 192).

84. The British Geriatrics Society particularly welcomed the involvement of the courts. "The courts play a vital role in interpreting the law in individual cases. Judgments stimulate debate among the medical profession and the public and raise the awareness of the complex issues involved. The custom of legal precedence is a better method of decision-making as judgments are based on actual events and conditions rather than assumed, as they would be by a statute" (p 26). The Joint Ethico-Medical Committee of the Catholic Union of Great Britain and the Guild of Catholic Doctors also welcomed the role of the courts in protecting vulnerable people, and in requiring doctors to "submit their views for legal interpretation" (p 126).

85. Some other witnesses did not welcome judicial involvement, mainly because of the courts' reliance on medical opinion. A notable example of such reliance, which still carries much weight, was the case of *Bolam v. Friern Hospital Management Committee*² in which it was held that a doctor who had acted in accordance with a responsible body of medical opinion was not guilty of negligence. The same principle was adopted in *Re F*³ when it was held that a doctor caring for an incapacitated patient should make treatment decisions in the patient's best interests, in accordance with a responsible body of medical opinion.

86. ENABLE⁴ said "the ordinary courts are not...a genuinely independent safeguard. Almost invariably, they have either explicitly followed medical opinions or simply referred decisions back to doctors...Unless guidance can be developed elsewhere which the courts can apply, it is difficult to see them playing a useful role" (p 91). Professor Sheila McLean suggested that "issues of life and death are not ultimately referable to current, reasonable or even responsible medical practice at any given time and the temptation to use such considerations is to be resisted. It is for the law and not the clinician to reach such conclusions and it is for the community and not the physician or nurse to face and shoulder the moral burden of such decisions" (P 146)⁵. ENABLE said that "the unique status given to the views of medical professionals is misconceived". They suggested that there should be a distinction between the medical prognosis and the ethical decision on treatment, since individual doctors would hold different views and relying on their judgment would give inequitable results (p 90). Similarly, the SPUC said "reliance on professional practice as the guide to law and ethics...is far from unproblematical. Professional practice should follow law, and law follow ethics, rather than *vice versa*" (P 234).

87. Christian Action Research and Education (CARE) said "it is not in the general public's interest as patients for the courts to be involved in the sensitive decision-making needed at the end of life", in part because of consequential delay and in part because of the risk of more litigation leading to "a less patient-centred approach" as in the United States of America (p 47)⁶. The

¹ P 111; p 4.

² [1957] 1 WLR 582.

³ [1990] 2 AC 1.

⁴ An organisation concerned with the welfare of people with learning disabilities.

⁵ See also P 147; Q 415.

⁶ See also Dr David Cook, P 173.

Christian Medical Fellowship said “we see the law as an inappropriate instrument for the sensitive decision-making needed in situations at the end of life...we would prefer no involvement of the courts except in maintaining a prohibition on intentional killing” (p 68).

88. The SPUC suggested that the judgments in the Bland case were “not an organic development of the common law, but legislation by judicial fiat...it would be undemocratic for a situation to develop in Britain like that in the United States of America where the cause of non-voluntary euthanasia has been advanced through the courts” (P 241).

RESOURCE ALLOCATION

89. The availability of resources inevitably influences the type and sophistication of health care which is offered in any society. The Department of Health said “resource allocation has no part to play in decisions concerning the withdrawal of an individual’s life-prolonging treatment. The doctor is obliged to do the best he can for the patient under his care” (P 14). The BMA expressed concern that resource considerations would in future dominate decision-making, and stressed that medical judgments “should be made when clinically appropriate, not when funds run out”. They said that it was the responsibility of society to ensure that resources were available to provide patients with the most appropriate care (Q 111) and emphasised the importance of open debate in ensuring that resource constraints were not used to restrict clinical freedom (Q 112). Other witnesses also emphasised that resource considerations should play no part in decisions about the treatment or care of individual patients¹.

90. ENABLE were concerned that decisions about withdrawal of treatment were sometimes made on the basis of “the cost to society of continuing to care for a person if they live” (p 90). They feared that such a consideration was prejudicial to the interests of disabled people. “It is not acceptable for treatment to be withdrawn on the ground of lack of resources. We accept that there may be some types of treatment which the NHS cannot afford. However, where treatment is available, it should be available to all regardless of disability” (p 89).

SOME ARGUMENTS FOR AND AGAINST EUTHANASIA

91. In this section we summarise the arguments which witnesses deployed specifically in support of, or in opposition to, decriminalisation of euthanasia. However, much of the evidence which we have already discussed is also relevant to these arguments.

Autonomy and individuality

92. The chief argument of the VES in favour of euthanasia “is driven by modern concepts of personal autonomy, choice and the rights of the individual”. They pointed out that “expectations about the degree of control an individual may exercise over his or her own life have risen greatly” and that for many this extended to life’s ending as well (P 85).

93. Professor Dworkin also emphasised the role of autonomy and individual decision-making in matters of life and death. He said “I am in favour of choice because people disagree about what kind of a death is meaningful for them. I, myself, believe that what sort of a death is right for a particular person and gives the best meaning to that person’s life, largely depends on how that life has been lived, and that the person who has lived it is in the best position to make that decision” (Q 477). He advocated euthanasia as an option for those people who felt that to be kept alive in a situation which they found unacceptable would be harmful to their lives as a whole, cheapening what they had valued (Q 451). He said that many people would not wish to continue in a state of heavy sedation, if such were necessary for the control of pain, or in any form of permanent unconsciousness (Q 458). He said “what counts as suffering is ending a life, or allowing a life to linger, possibly for decades, in a form which the person whose life it is, and those closest to her or

¹ See for example PP 74, 172; p 263.

him, think is an insult, or a travesty" (Q 459). This view was supported by some of the letters from the public which we received¹.

94. Professor Dworkin suggested that arguments against euthanasia on the grounds that vulnerable people could be harmed by its practice, failed to recognise that other people could be harmed by a refusal to permit it (Q 452)². The British Humanist Association suggested that "to refuse a considered request is to treat that person with contempt" (p 32).

95. The BMA on the other hand argued that, although denial of a right to euthanasia ran counter to the concept of autonomy and self determination, "granting the desires of some entails an unacceptable cost for others and therefore is contrary to other ethical imperatives such as the concept of justice" (P 31)³. HOPE also pointed out that "we live in a society that is more than just a group of autonomous individuals" and that therefore individual rights are balanced by social responsibilities (P 106). The Bishops said "A positive choice has to be made by society in favour of protecting the interests of its vulnerable members even if this means limiting the freedom of others to determine their end" (p 113). Other witnesses made the same point⁴.

96. The Bishops also argued that the extension of autonomy to allow euthanasia would limit the autonomy of doctors, since "patients cannot and should not be able to demand that doctors collaborate in bringing about their deaths" (p 113). The SPUC said that "licence for euthanasia would quickly become a duty for health-care workers to take part in it, thereby limiting their personal autonomy and denying respect for private conscience" (P 237).

Sanctity of life

97. As we have seen, witnesses expressed a variety of views about the value of life⁵. In addition, some witnesses argued strongly against euthanasia on specifically religious grounds. The Bishops said "Because human life is a gift from God to be preserved and cherished...both Churches are resolutely opposed to the legalisation of euthanasia even though it may be put forward as a means of relieving suffering" (p 114). The Reformed Presbyterian Church of Ireland said "Life is to be viewed as his [God's] gift, given and taken again according to his sovereign will. It is thus not at the disposal of any human being" (p 284).

98. The VES rejected the absolute concept of sanctity of life as one to which only a minority subscribe, and to which even the major religions see exceptions in certain categories of justified killing (P 85). They suggest that "the phrase 'respect for life' may reflect the present day consensus on the matter more accurately than the absolutism of 'sanctity of life'" (P 86).

99. The British Humanist Association suggested that sanctity of life was not a principle on which legal structures should be based, since it depended on a religious outlook which not everyone shared. They suggested that "it is particularly hurtful to require someone who does not believe in God or afterlife to suffer intolerable pain or indignity in deference to a God or afterlife he does not accept" (p 28).

Public opinion

100. The VES cited both public and professional support for euthanasia, in the form of opinion polls (P 90, Q 188) and press articles. They suggested "that there is an informal humane consensus on this matter is now beyond doubt" (P 86) and that legislation is necessary "to bring the law into line with current thinking on right and wrong" (P 87). They said that the issue of euthanasia "is now too much one of public concern to be left to the traditional discretion of the medical profession

¹ See Appendix 2.

² This point of view is thoroughly explored in Ronald Dworkin, *Life's Dominion* (London: Harper Collins, 1993).

³ See also Q 107.

⁴ See for example P 168; pp 43, 93.

⁵ See paragraphs 34 to 39.

behind closed doors” (P 87). Mr Ludovic Kennedy also suggested that public opinion was increasingly strong in support of euthanasia (Q 319). Professor Jennett reminded us that both the Appleton Conference¹ and a majority of the Institute of Medical Ethics Working Party had recently declared that euthanasia could be an ethically justifiable option in certain circumstances, and drew attention to other indications of a shift in some sectors of professional opinion (pp 121, 122). Dr Tim Helme² also drew attention to a number of surveys which suggested increasing support for euthanasia (PP 271, 272). He suggested there was a danger of the law falling into disrepute if it did not change to keep in line with public opinion (Q 694).

101. It must be noted however that the results of the public opinion polls which the VES and Dr Helme cited are far from decisive. As with any poll, the result produced is much influenced by the way in which the question is worded. It may be doubted whether the expression “to receive medical help to an immediate peaceful death” is readily understood to mean euthanasia; the omission of the word “immediate” from the 1993 poll (P 90) may be thought to cloud the matter still further.

Relationship between doctor and patient

102. The existence of a trusting and open relationship between doctor and patient is of particular importance when the patient is terminally ill and decisions must be made for care towards the end of life. The VES suggested that “any change making it easier for doctors openly to carry out their patients’ wishes can only reinforce confidence on both sides” (P 88). Some other witnesses agreed³.

103. More witnesses however felt that the relationship between doctor and patient would be undermined if the doctor was empowered to practise euthanasia, even under the strictest of controls⁴. The BMA said “if doctors are authorised to kill or help kill, however carefully circumscribed the situation, they acquire an additional role, alien to the traditional one of healer. Their relationship with all their patients is perceived as having changed and as a result some may come to fear the doctor’s visit” (P 29)⁵.

104. The Lihacre Centre suggested that the practice of euthanasia would corrupt the character of doctors, and encourage them to view some patients as lacking inherent worth. This would undermine “a disposition indispensable to the practice of medicine: the willingness to give what is owing to patients just in virtue of their possession of basic human dignity” (p 172).

Advances in medical science

105. The VES cited developing medical technology as a factor fuelling support for euthanasia. “Having created the situation in which lives are routinely saved, transformed or prolonged by medical intervention, we can hardly pretend that the process of dying, and that alone, must be left to nature” (P 85)⁶. Mr Ludovic Kennedy suggested that advances in medical techniques meant that “the dominant fear today is of being denied release from a prolonged period of painful, distressing and undignified dying” (Q 319). This point was supported by a number of individual members of the public who wrote to us, particularly those who had witnessed the difficult death of a family member⁷.

¹ See footnote 3 at paragraph 54.

² A consultant psychogeriatrician.

³ See for example Q 325; p 32.

⁴ See for example P 168; pp 41, 94, 209, 218. See also Appendix 2.

⁵ See also P 32; pp 37, 114.

⁶ See also Q 188.

⁷ See Appendix 2.

"Slippery slopes"

106. The so-called "slippery slope" argument was clearly put by the BMA. They said that "by removing legal barriers to the previously 'unthinkable' and permitting people to be killed, society would open up new possibilities of action". They said that "any moral stance founded on the permissibility of active termination of life in some circumstances may lead to a climate of opinion where euthanasia becomes not just permissible but desirable. Once active termination of life is a matter of choice for competent people, the grounds for excluding non-competent people from such treatment become harder to defend" (P 32). A number of other witnesses made a similar point¹. Sir Robert Kilpatrick observed that "one of the great problems is always to work out the implications of a change, because they may be much more far reaching than one can see". He cited abortion as an example, saying that the number of abortions performed each year far exceeded that expected at the time legislation was passed (Q 396). Dr David Cook made a similar point: "What began in 1968 as offering permission for doctors to perform abortions under certain restricted terms has now become an expectation...that abortion is available on demand...there has been a slippery slope when legislation about justified killing has been introduced". He also spoke of the human inclination always to go beyond any established limit (P 174).

107. The Reformed Presbyterian Church of Ireland feared that voluntary euthanasia would lead to a descent of the "slippery slope" because of the need for concurrence by the doctor. "The ultimate decisive factor is the patient's perceived quality of life—ie that his life is not worth living—not his request for death...there is no logical reason, once voluntary euthanasia is allowed, why the practice may not be extended to cases where no request has been made, if in the doctor's judgment that is the best course of action for all concerned" (p 284).

Other arguments

108. The RCN were concerned for the wellbeing of the vulnerable. "We have daily contact with some of the most vulnerable people in society at the hardest times of their lives and we know that many of the problems that they suffer, they suffer as a result of poor resourcing. If euthanasia were an alternative then the imperative to provide the resources for those people, whether it is the education of doctors in pain control or provision of decent facilities for elderly people with physical illness, would be cut at a stroke" (Q 160)².

109. A few witnesses considered that the knowledge that euthanasia was available as a last resort would comfort and reassure many patients who feared the future, though in the event few might take that option³. The Voluntary Euthanasia Society of Scotland (VESS) said "the ability 'to leave by the door marked Exit', should the final need arise, gives many patients the courage to go on much longer" (p 269). On the other hand Mr Kennedy, although an advocate of euthanasia, acknowledged that "some people are really terrified that if this becomes law they will be in jeopardy" (Q 333).

110. HOPE suggested that a request for euthanasia was often not intended but "almost always expresses, How much value am I to society?" (Q 265). Ms Alison Davies⁴ suggested that the appropriate response to patients requesting euthanasia was "to help them to regain a sense of the worth of their own life, but we should not collude with their despair and hopelessness" (Q 681). The British Geriatrics Society said "although elderly severely ill patients may sometimes ask to be allowed to die, they very seldom request active procedures to ensure that they do" (p 25).

¹ See for example PP 98, 99; pp 37, 69, 93, 173.

² For similar views see also P 107; p 41.

³ See for example Q 325; p 33.

⁴ A representative of the SPUC Handicap Division.

111. Dr Helme suggested that the practice of euthanasia would allow patients who so wished to die at home rather than in an institution (Q 693). This was also mentioned as a benefit in some of the letters which we received¹.

112. A number of witnesses emphasised that the time of dying could be a positive and constructive phase of life, which could be sacrificed if euthanasia were an option². The BMA said that "if handled well, the crisis of impending death can be a time of personal growth and reconciliation for all those close to the dying person" (P 32). This point was also made by a number of individual members of the public in their letters to us³.

113. The Evangelical Alliance and the British Evangelical Council suggested that if euthanasia were permitted the consequences of misdiagnosis would be particularly grave. "If a patient, on hearing a diagnosis of terminal illness, were to request and be granted euthanasia when no such terminal condition existed, a tragedy would have occurred" (p 94).

114. The Handicap Division of the SPUC suggested that any system of criteria by which some requests for euthanasia were accepted and acted on, and others not, would demonstrate the view that certain people "are right to believe their lives are worthless" (P 249)⁴. The Division drew attention to the fact that most proponents of euthanasia would limit it "to those who are either terminally ill or incurably disabled...This implies that sick and disabled people are "right to want to die" and "better off dead" whereas the able-bodied who express suicidal wishes are "wrong to want to die" and should be helped to value their lives" (P 248). The Linacre Centre made a similar point: "Any doctor who feels that a given patient still has a worthwhile life to live will not accede to a request for euthanasia from that patient. By contrast, it is precisely the judgment that a patient no longer has a worthwhile life which will seem to justify euthanasia" (p 162).

Proposed safeguards

115. Dr Helme set out a thorough and considered proposal for a framework in which, he suggested, euthanasia might be safely practised. He suggested that the law "could allow a more limited right to be relieved of extraordinary suffering...a liberty to request euthanasia (rather than a right to demand it) reserved for exceptional circumstances" (ME 44). His proposal was for legislation to provide doctors who performed euthanasia with a "special defence" to criminal charges if they acted in accordance with one of two procedures. The first would involve notification in advance of the intention to perform euthanasia, and then retrospective scrutiny of the circumstances to ensure that the doctor had acted in accordance with prescribed conditions; if not, prosecution would follow. The second procedure, appropriate in cases where the doctor was more uncertain of the circumstances, would involve application to a Tribunal which would consider all the circumstances in advance of the action and make a recommendation; a doctor who performed euthanasia in accordance with a recommendation of the Tribunal would not have an automatic right to kill, but could usually expect not to be prosecuted. Dr Helme suggested that an advantage of his proposal was that, by making it clear that the practice of euthanasia was a statutorily controlled procedure quite separate from ordinary medical practice, there could be no pressure to participate on doctors who objected on grounds of conscience (Q 697).

116. The main safeguard proposed by the VES was that euthanasia should be performed only if the patient had, at least 30 days earlier, signed a declaration requesting it, and currently repeated that wish. They also suggested that where the request was prompted by treatable depression or anxiety, this should be observed and dealt with by the attending doctor (Q 192). This point was also made by Mr Kennedy (Q 323).

¹ See Appendix 2.

² See for example P 105.

³ See Appendix 2.

⁴ See also Q 677.

117. Professor Dworkin considered that it would not be possible always to be totally confident that a request for euthanasia was truly voluntary and not the result of pressure or coercion. But he suggested that a combination of legislative provision and social response could minimise the likelihood of such abuse (Q 442). If euthanasia were permitted, "the message should be one of individual responsibility...the reason for permissive legislation is not that we collectively think that is the decent thing to do, but that we collectively want people to act out of their own conviction" (Q 455).

118. HOPE expressed doubts that society could ever be sure that a patient requesting euthanasia had made a choice that was "free, fully-informed and rational". They suggested that a patient's choice could be improperly influenced by depression, confusion, dementia, a feeling of being burdensome to others, or even by direct pressure from others (P 107)¹. The Bishops expressed similar concern (p 113).

EUTHANASIA IN THE NETHERLANDS

119. The Netherlands is the only country in which euthanasia is openly practised in accordance with formal regulation. Evaluation of experience there is therefore useful to any assessment of the likely effects of the practice of euthanasia, allowing of course for social and cultural differences, and for differences in the health-care environment.

120. Euthanasia is a criminal offence in the Netherlands, but for some years it has been understood that doctors would not be prosecuted for it provided they acted in accordance with a number of criteria. These have recently been enshrined in legislation by amendment of the Burial Act 1955², following the report of the Remmelink Committee in 1991. That report drew on a nationwide survey of the practice of euthanasia, summaries of which have been published in English in the professional literature.

121. The survey found that about one-third of persistent, explicit requests for euthanasia were agreed to. In the remaining two-thirds either alternatives were found which made the patient's life bearable again, or the patient died naturally before any action was taken. Of all deaths in the Netherlands, 1.8 per cent (that is 2300 cases annually) were the result of voluntary euthanasia. There were a further 400 cases (0.3 per cent of all deaths) of assisted suicide. These figures contrast with the number of reported cases of euthanasia and assisted suicide, which were 454 in 1990 and 591 in 1991³. Of the doctors interviewed for the study, 54 per cent said that they had practised voluntary euthanasia or had assisted a suicide; many said they would be reluctant to do so again, and then only in the face of unbearable suffering and if there was no alternative⁴.

122. In 0.8 per cent of all deaths (that is 1000 cases annually) a patient's life was terminated without the explicit request of the patient⁵. In 41 per cent of those cases the patient was not competent to discuss the proposed course of action; in 83 per cent it was discussed with the patient's relatives. In 86 per cent of cases life was shortened by a few hours or days at most. Of the doctors interviewed, 27 per cent said that they had performed such an action at least once⁶. The Dutch Minister of Justice has announced that, as a general rule, doctors reporting that they have ended a life without the patient's request will have to face prosecution; but it may be doubted whether, in view of that announcement, such actions will ever be reported.

¹ For similar views expressed by other witnesses see PP 175, 237; p 209.

² For a fuller account of the position see Appendix 3.

³ Source: Ministry of Welfare, Public Health and Culture, Netherlands.

⁴ van der Maas PJ, van Delden JJM, Pijlenborg L, Looman CWN. Euthanasia and other medical decisions concerning the end of life. *Lancet* 1991;338:669-74.

⁵ The Dutch do not class such acts as euthanasia, which they define as being strictly voluntary.

⁶ Pijlenborg L, van der Maas PJ, van Delden JJM, Looman CWN. Life-terminating acts without explicit request of patient. *Lancet* 1993;341:1196-99.

123. A number of witnesses cited these findings in support of their view that tolerance of voluntary euthanasia leads inevitably to involuntary euthanasia. HOPE suggested that this should be sufficient to stop the United Kingdom legalising euthanasia (P 113). The Christian Medical Fellowship said "the evidence from the Netherlands makes it clear that where voluntary euthanasia is tolerated, euthanasia which is not voluntary will follow" (p 65)¹. On the other hand the VES suggested (P 86) that much concern arose because of misinterpretation of the survey's findings. The survey's authors have refuted the suggestion that their work demonstrates the inevitable descent of a slippery slope: "we simply do not know" whether termination of life without the request of the patient "occurred less or more often in the past. Nor can we safely predict the incidence in the near future. Nor do these numbers provide any comparison with other societies where euthanasia is not decriminalized"².

124. The VES suggested that the fact that euthanasia was carried out in only about one-third of the cases where it was requested showed how tightly the matter was controlled (Q 191). Mr Kennedy also considered that the Dutch safeguards were adequate (Q 322). HOPE on the other hand said that evidence from the Netherlands demonstrated that euthanasia could not be policed. They pointed out that any check on the circumstances in which euthanasia was performed depended on the doctors notifying their actions to the authorities, but that the number of euthanasia cases reported each year was only a fraction of the number discovered by the survey (P 113). The Dutch Ministry of Justice noted that the rate of notification was rising significantly as the criteria for euthanasia were clarified and doctors were no longer in doubt about their position, and that 1318 cases were reported in 1992³. However it is not evident whether the proportion of cases which is notified has increased, or whether the incidence of euthanasia has increased overall.

125. Dr John Keown⁴ has argued that the Dutch criteria for euthanasia are far from precise, and that the circumstances in which euthanasia is practised are therefore far from effectively controlled⁵. He suggested, for example, that the requirement that "the request for euthanasia must come only from the patient and must be entirely free and voluntary" was not adequately defined, and there was nothing to preclude euthanasia being first suggested, or even recommended, by the doctor. He further suggested that the requirement that the request "must be well considered, durable and persistent" was equally unspecific, and cited a survey which showed that in 13 per cent of cases studied the interval between the first request for euthanasia and its performance was no more than a day.

126. HOPE suggested that the availability of euthanasia in the Netherlands was one reason why palliative care had been little developed there (P 113). Equally it might be suggested that euthanasia is resorted to because care of the dying is less than optimal. On the other hand the Rummelink Committee concluded that "pain is not the most common motive for a request for the termination of life. The fear of total degeneration and the very natural wish to be able to pass away peacefully are just as important reasons"⁶.

"MERCY KILLING"

127. A number of witnesses considered the question whether, in the absence of any change in the law regarding euthanasia, certain types of deliberate killing should be treated differently from others. The Home Office discussed past proposals that there should be a reduced degree of culpability for "mercy killing" (P 17). Their view was that to take motive into account would give rise to argument (Q 43). They also suggested that the issue of "mercy killing" arose only

¹ For a similar view see also p 69.

² van Delden JJM, Pijnenborg L, van der Maas PJ. Dances with data. *Bioethics* 1993;7(4);323-329.

³ Source: Ministry of Welfare, Public Health and Culture, Netherlands.

⁴ Lecturer in law, University of Leicester.

⁵ The law and practice of euthanasia in the Netherlands. *Law Quarterly Review*, 1992;108;51-78.

⁶ *Medical practice with regard to euthanasia and related medical decisions in the Netherlands: Results of an inquiry and the government view*, produced by the government of the Netherlands.

infrequently, and that the courts often found diminished responsibility which enabled less stringent penalties to be imposed (P 17). The CPS told us that it was not common for relatives or health-care staff to volunteer information in cases which might be regarded as “mercy killing”, so that there was often no police investigation (p 81). They also drew attention to other evidential difficulties in cases of that kind (p 82). They reiterated that even in respect of a “mercy killing” by a relative the CPS “would feel obliged under the law as it stands now...to proceed with the matter and for it to be brought before the court as a case of murder” (p 83).

128. Statistics which the Home Office supplied (Table on P 18 and Supplementary Memorandum on P 25) show that between 1982 and 1991 “mercy killing” was an issue in 22 cases of homicide (in none of these cases was the defendant a doctor—relatives or other acquaintances of the patients were involved). In all but one of those cases (where the charge was infanticide) proceedings were begun on a charge of murder, but in only one case was a conviction for murder, and a sentence of life imprisonment, the outcome. In the other cases where a conviction resulted lesser offences were substituted and most of the sentences were for periods of probation or suspended imprisonment. These statistics suggest two possible conclusions: on the one hand it might appear that existing provisions are sufficiently flexible to allow appropriate outcomes to be achieved; on the other hand it might be suggested that the inadequacy of existing provisions is shown by the way in which the courts and prosecuting authorities apply them.

129. HOPE suggested that to introduce a new offence which took account of motive, could encourage medical misconduct (P 112). Mr Kennedy resisted the idea of a new offence of mercy killing, since it still implied an act against the will of the person whose life was ended, and so did not acknowledge the crucial voluntary element of euthanasia as he advocated it (P 132). The VES said that a new offence “would be better than nothing” failing the decriminalisation of euthanasia, but that it would be unsatisfactory because it focussed on the perpetrator rather than on the wish of the patient (Q 214). Sir Stephen Brown agreed to a suggestion that it would be useful if the law provided for different degrees of killing, one of them being mercy killing (Q 312).

PENALTY FOR MURDER

130. The fact that a conviction for murder carries a mandatory life sentence has been widely debated, not least by a Select Committee of the House¹. That Committee recommended abolition of the mandatory life sentence, which would allow judges to take account in sentencing of the particular circumstances of each case. Its report set out clearly the arguments for and against the retention of the mandatory life sentence. The most important objection was that, as the crime of murder is presently defined, the mandatory sentence applies to an enormous range of offences. The Committee quoted Lord Hailsham of St Marylebone’s speech in *R v. Howe*, in which he said: “Murder, as every practitioner of the law knows, though often described as one of the utmost heinousness, is not in fact necessarily so, but consists in a whole bundle of offences of vastly differing degrees of culpability, ranging from brutal, cynical and repeated offences...to the almost venial, if objectively immoral, ‘mercy killing’ of a beloved partner².”

131. Among the factors which carried most weight with that Committee in reaching its decision was the weight of judicial opinion in England and Wales. The then Lord Chief Justice, Lord Lane, and 12 out of the 19 High Court and Court of Appeal judges who expressed a view were in favour of a discretionary sentence for murder. There is, in fact, a long tradition of judicial support for a discretionary sentence for murder, and the great majority of judges who took part in the vote in the House on the Murder (Abolition of Death Penalty) Bill in 1965 were in favour of a discretionary sentence.

132. Since the publication of the report on murder and life imprisonment, the House has had two opportunities to consider the law in this area. The first was in the debates on the Criminal

¹ *Murder and Life Imprisonment*, Report of the Select Committee, Session 1988-89, HL Paper 78-I

² [1987] 1 AC. 417 at 433.

Justice Bill in 1991. An amendment to that bill which provided that, in future, no court should be required to sentence a person convicted of murder to imprisonment for life was carried against the Government by a large majority. Among the supporters of the amendment were two former Lord Chancellors, the Lord Chief Justice, the Master of the Rolls and five Lords of Appeal. The amendment was overturned by the House of Commons voting strictly on party lines. The second attempt in recent years to abolish the mandatory life sentence was in a Private Member's Bill¹, introduced by Lord Ashley of Stoke. This was given a Second Reading on 8 February 1993, when the only speaker against the bill was the Government spokesman. With only a single dissident, the bill also completed its later stages and was sent to the Commons. In the debates on both of these bills, the main argument put forward by the Government was that murder is a "uniquely heinous crime".

133. Most recently, an independent committee chaired by Lord Lane has repeated the call for abolition of the mandatory life sentence. That Committee concluded that it was "wrong to require judges to sentence all categories of murderer in the same way, regardless of the particular circumstances of the case" and "wrong to require the distinction between the various types of murder to be decided (and decided behind the scenes) by the Executive". It suggested that one advantage of a change in the law would be to "make it unnecessary for unsavoury devices to be adopted to evade the difficulties posed by the mandatory life sentence", the charge of manslaughter on the grounds of diminished responsibility being the prime example².

134. In evidence to us, the Home Office repeated their view that "the period of time spent in custody varies greatly from case to case and that in practice the system is flexible enough to ensure that custody is not unjustifiably prolonged" (P 17). However in 1990 and 1991 no prisoner convicted of murder served less than six years of a mandatory life sentence³.

135. The VES reiterated the case for change. They said that the "crudity of the mandatory sentence...in no way reflects the enormous moral gulf which in reality separates the aggressive murder from the 'mercy killing' carried out in response to a sufferer's own wish" (P 87). They also argued that "the present rigidity of the law has led to hypocritical and degrading pleas which obscure the true facts of cases" (P 87) although when asked to explain this they gave few details (Q 205 and footnote).

PALLIATIVE CARE AND THE HOSPICE MOVEMENT

136. In the United Kingdom palliative care has been developed to a high standard by the hospice movement. As the National Council for Hospice and Specialist Palliative Care Services ("National Hospice Council") said, "hospice is a philosophy not a building" (P 211). The movement has inpatient units, but also comprises day centres, home support teams and hospital support services. What is common to all of them is a "concept of 'holistic care' concentrating not only on the physical needs of the patient, but also on emotional, spiritual and social needs" (P 190). Also important is the "emotional support to relatives and friends throughout the patient's illness and in bereavement" (P 2).

137. The elements comprised in good palliative care are set out by the Association for Palliative Medicine (P 190). The National Hospice Council also makes an important point: "palliative care affirms the value of the individual to society and endeavours to maintain the patient's sense of self-worth by demonstrating through sensitive and compassionate care that he or she is still of value to others" (P 209). Dr Ilora Finlay⁴ explained that "one of our roles in supporting people who are facing increasing disability is to help them set positive attainable goals so they can maintain their sense of personhood" (Q 528).

¹ Penalty for Murder Bill [HL] HL Bill 58, Session 1992-93.

² Report of the Committee on the Penalty for Homicide, Prison Reform Trust, London 1993, page 5.

³ Lord Windlesham, Life sentences: law, practice and release decisions, 1989-93. [1993] Criminal Law Review 653.

⁴ Medical Director of a Marie Curie Hospice, and Honorary Secretary of the Association for Palliative Medicine.

138. A number of witnesses expressed their concern that any move which society might make towards euthanasia would undermine the work of the hospice movement, and lessen commitment to improving and extending care for the terminally ill¹. The National Hospice Council said that it might “reduce or even remove the incentive for further improvements in patient care” and that what was needed instead was “greater realisation of what can be done to alleviate physical and mental suffering, and a determination on behalf of health care professionals and society to do it” (P 210).

139. LIFE characterised the campaign for euthanasia as a “call...from the past”, saying that the growth of the hospice movement and advances in pain and symptom control made euthanasia unnecessary (P 98). Other witnesses echoed this view². Mr Peter Byrne³ suggested that rather than permit euthanasia “it is much better to adopt a social policy of investment in the development of palliative medicine to whittle away at those cases where euthanasia appears to be the only or best option for care” (p 37)⁴.

140. The VES resisted the idea that hospices made euthanasia unnecessary. They pointed out that hospices treat patients with only a limited range of conditions, and suggested that for many people they had nothing to offer (Q 217). The British Humanist Association said that despite the admirable work of the hospice movement, there was still a need for voluntary euthanasia since hospices could not relieve all suffering (p 32). Mr Kennedy observed that, even with the best palliative care, patients could reach “a stage where they simply do not want to go on”, often as much because of secondary conditions such as incontinence as because of pain (Q 321). Professor Dworkin observed “the good hospices do offer people a way to find a meaning in their death, but it is not everybody’s sense of what a meaningful death would be” (Q 477).

141. Dame Cicely Saunders⁵ said that patients discharged from a hospice would be given a supply of drugs to continue to control their symptoms. Rarely, a patient would use that supply of drugs to commit suicide (Q 557).

142. The funding of the hospice movement was a matter of concern to some witnesses. Much of the movement’s resources comes from voluntary sources, but just over £32 million of government funding was allocated for 1993-94 (P 4). This was ring-fenced for spending by health authorities on hospices and similar services, but in the next financial year the funds will not be ring-fenced but will be subject to “purchaser-provider contracts” (QQ 21, 24). The Department of Health said that it was a priority for the NHS “to ensure the agreement of service contracts for palliative care services to meet the needs of terminally ill people” (P 14). The Medical Ethics Committee of the Order of Christian Unity urged “NHS funding or at least a grant system to hospices” (p 197).

143. The availability of hospice care across the country is not uniform, but growth in the movement in recent years has been rapid. In particular increased emphasis on the role of home-care nursing and day-care services, as well as beds in hospice buildings, has improved coverage. The National Hospice Council gave us details of the level of services available: 193 in-patient units, over 400 home-care teams, over 200 day hospices, 216 hospital support teams (P 211).

144. The need for the best practice of palliative care to be widely disseminated throughout the health-care professions was discussed by witnesses⁶. The Association for Palliative Medicine and the National Hospice Council discussed some of the educational initiatives being undertaken (QQ 542, 574). The Association explained their object that every health authority should have “a sufficient body of skill and knowledge in palliative medicine to which patients within hospitals,

¹ See for example PP 32, 113, 175, 243; pp 42, 68, 94, 172, 285.

² See for example PP 112, 175; p 209.

³ Senior Lecturer in the Philosophy of Religion, King’s College, University of London.

⁴ See also p 286.

⁵ Founder and Chairman of St Christopher’s Hospice, and Honorary Chairman of the National Council for Hospice and Specialist Palliative Care Services.

⁶ See for example QQ 145,501; p 197.

hospices or at home can have access...the idea is that we are an integrated part of the service" (Q 540)¹. They were also optimistic about the progress made to date: "there is an increasing understanding of...what we have to offer...We are reaching more people all the time" (Q 541).

145. Between 90-100 per cent of patients cared for in hospices are suffering from advanced malignant disease, and the remainder mostly from motor neurone disease (Q 559-561). Dame Cicely explained that this concentration was partly historical: "if we were going to do soundly-based research from which other people would learn and interpret and develop in their own setting we would have to have a certain amount of focus" (Q 564). But Dr Doyle made clear that the hospice "philosophy of whole person care" could be applied equally to patients with non-malignant disease (Q 561) and pointed out that palliative care support teams and consultative services in hospitals were increasingly seeing patients with a whole range of other conditions (Q 562).

RELIEF OF PAIN

146. The BMA acknowledged that "for a very small minority of patients, terminal pain and distress may be resistant to complete control" (P 31). They therefore urged that effort should be focused on seeking to improve pain management. They also urged doctors to master all available techniques and to seek expert advice promptly whenever necessary (Q 100).

147. The RCN said that there was "a large cohort of patients" dying in distress (Q 138), but suggested that this was largely due to failure to implement the wide range of pain-relieving techniques available, including complementary therapies such as hypnotherapy and aromatherapy (Q 136). The RCN were themselves addressing that failure by means of a training programme (Q 138).

148. LIFE said that, in a hospice at least, pain was not a problem. Pain could be relieved provided the patient was prepared to be made drowsy, but a patient who wished to remain conscious might have to put up with more pain (Q 239). A similar point was made by Dr Twycross, for HOPE (QQ 263, 264). Sir Robert Kilpatrick also said that "it is very unusual in these days not to be able to control pain" (Q 368) and that in the last resort sedation was an option (Q 369).

149. A survey by Madeleine Simms of the Institute for Social Studies in Medical Care found that many professionals caring for patients with AIDS considered that their pain and symptoms could not all be satisfactorily relieved (pp 232-234). However Ms Simms acknowledged that "doctors or nurses specialising in pain control methods would achieve better results" (p 234). The BMA suggested that the application of measures developed in the hospice movement would be advantageous for management of AIDS and other progressive incurable diseases causing severe distress and not necessarily pain, but said that this "may involve sedation in the later stages of disease" (p 33).

150. The Association for Palliative Medicine said that proper pain relief depended on a team approach so that the specific skills of all specialities—including, where appropriate, anaesthesia, radiotherapy and oncology—could be brought to bear (Q 526). They emphasised the dangers of doctors working in isolation, without recourse to appropriate specialist advice about methods of pain control (Q 527).

151. Dr Janet Hardy² said that six per cent³ of patients in the Unit had symptoms which could not be completely relieved (Q 598). None died in uncontrolled pain, and sedation was often used (Q 600). Dr Hardy observed that often a symptom such as breathlessness could not be controlled completely, but sufficiently to give the patient relief and comfort (Q 613). Only with a sudden, acute crisis would a patient be in screaming agony (Q 614).

¹ See also Q 576.

² Head of the Royal Marsden's Palliative Care Unit.

³ The significance of this figure was modified by the discussion which followed.

152. Dr Steven Greer¹ said that in his experience there were a small number of patients with severe intractable symptoms which could not be relieved. "Certain symptoms...cannot be adequately relieved by treatment even when given by specialists such as palliative care physicians and anaesthetists...great distress and suffering is unavoidable in these unfortunate circumstances" (P 221). He argued that in such rare cases euthanasia should be considered where requested by the patient (Q 595), in preference to heavy sedation (Q 603). However when pressed he made clear that he would not wish to use a non-therapeutic agent (QQ 623, 624).

153. Dr Ray Powles² could recall from his long experience only one patient for whom "there possibly could have been a case for euthanasia" and, with hindsight, treatment with diamorphine could have controlled his symptoms (Q 608).

154. Dr John Morley³ said that of the patients referred to the Pain Relief Centre "about 15 per cent...are still not satisfactorily relieved of pain" (p 287). He also described a case of paradoxical pain, in which the patient's pain grew worse rather than better when large doses of heroin were given. He suggested that paradoxical pain probably occurred because of differences in the way in which morphine is metabolised by different patients (p 287).

155. Quite apart from physical pain, dying people may suffer psychological, social or spiritual distress, perhaps as a result of loneliness or fear of dying (QQ 239, 526). Dr John Ellershaw⁴ emphasised the need to address all these aspects as part of "a concept of total pain" (Q 526). Befriending and counselling techniques may be used to alleviate such distress (Q 239).

PERSISTENT VEGETATIVE STATE

156. Advances in medical technology can give rise to new phenomena, since patients can be kept alive in circumstances where previously death would have been certain. The persistent vegetative state (pvs), which is sometimes the ultimate result of brain damage such that the patient loses all cognitive functions, is poorly understood⁵. The BMA observed that the difficulties of diagnosis of pvs are considerable (P 44). A reliable diagnosis requires a combination of techniques, and may only be confirmed after a considerable passage of time. Guidelines issued by the BMA recommend that a diagnosis should not be considered confirmed until 12 months have passed, and that the doctor making the diagnosis should seek the independent views of two other practitioners (P 57)⁶. The BMA said that "this is not a diagnosis that can be made in the early stages of the suspected condition, when all rehabilitative efforts must be made" (P 43)⁷.

157. Some witnesses suggested that some patients diagnosed as suffering from pvs could make a degree of recovery if properly cared for⁸. Dr Keith Andrews⁹ said "the potential for recovery is uncertain" (p 221). He cited a number of studies which suggested differing degrees of recovery in pvs patients after varying periods (pp 221-2)¹⁰. However the literature suggests that variations in diagnostic criteria may be significant, and that it may be possible to identify certain clinical signs, dependent in part upon factors such as the age of the patient and the nature and severity of the insult to the brain, which mark out those patients who might show some degree of improvement. However

¹ Director of the Psychological Medical Unit at the Royal Marsden.

² Head of the Royal Marsden's Leukaemia Unit.

³ Consultant Neuropharmacologist at the Pain Research Institute, Liverpool.

⁴ Consultant in Palliative Medicine at St Christopher's Hospice, and a representative of the Association for Palliative Medicine.

⁵ For a discussion of the diagnosis of pvs, and of other conditions with which it is sometimes confused, see Appendix 4. The differences between pvs and coma were discussed by the BMA (P 43).

⁶ See also PP 44, 45.

⁷ See also PP 45, 56.

⁸ See for example pp 223, 285; P 251.

⁹ Director of Medical and Research Services at the Royal Hospital and Home, Putney, which has a unit dedicated to pvs patients.

¹⁰ See also Keith Andrews, Recovery of patients after four months or more in the persistent vegetative state. *British Medical Journal* 1993; 306:1597-1600.

improvement is very rare where pvs has been diagnosed using all available techniques and has continued for 12 months¹. Improvement from an established pvs sufficient to restore to the individual significant motor, intellectual, verbal or cognitive skills does not occur.

158. Dr Andrews also noted that pvs patients can live for substantial periods. "Pvs, in itself, is not a terminal illness, any more than life itself is...[it is] a case of how long these patients *are allowed* to live rather than how long they *can* live...life expectancy is more influenced by the willingness to treat any infections and to feed adequately than by the direct effect of the brain damage" (p 222).

159. It might be suggested that definitions of death should be reconsidered, in the light of uncertainty created by new medical technology which gives rise to new human conditions². Traditionally death has been defined as the discontinuance of heart and lung function. Since medical technology has enabled these functions to be continued artificially, traditional definitions of death have been joined by the concept of "brain death"³. The accepted definition of the latter in the United Kingdom is the permanent functional death of the brain stem⁴; several witnesses explicitly indicated their acceptance of that definition⁵. General acceptance of the definition has resulted in brain-stem death being regarded as equivalent to death for the purposes of switching off artificial life-support mechanisms or removing organs for donation.

160. Some might argue that, since in pvs all those features which differentiate one person from another—personality, emotion, the ability to relate to others—are irreversibly lost, this too should be regarded as death. However such a proposal has obvious difficulties. Death of the brain's neocortex cannot yet be established with absolute certainty. Moreover to equate death with loss of psychological attributes such as, for example, awareness or possession of cognitive skills, would be to imply that being alive is to be understood in terms of the possession of such psychological attributes. Such an implication could have consequences for neonates and the severely disabled. The BMA considered these issues in their discussion paper on pvs (PP 46, 47).

161. Mr Francis Bennion⁶ suggested that legislation should provide that a patient in pvs "should in law be treated as dead even though it continues to be true that with medical assistance his body sustains its own life". He suggested that "because of new technology the death of a *person* now needs to be distinguished from the death of his or her *body*" (p 9). He explained that "it is inherent in legal doctrine, for sound reasons connected with the social purpose of law, that needs and expectations of the living should not be blocked by one who has in social reality, if not in physiological fact, departed this life" (p 11). He proposed the form which such legislation should take (p 10). The Patients Association said that "effectively, a person in pvs has finished their life as a human being" and that the withdrawal of life-supporting measures was therefore acceptable (p 208).

162. LIFE objected to the term persistent vegetative state (P 100). They expressed a preference for "persistent non-responsive state" (Q 233).

¹ See for example Bryan Jennett, Vegetative Survival: the Medical Facts and Ethical Dilemmas, *Neuropsychological Rehabilitation* 1993,3(2)99-108; Childs, Mercer and Childs, Accuracy of diagnosis of persistent vegetative state, *Neurology* 1993,43,1465.

² See for example p 215.

³ For a discussion of this, see Appendix 5.

⁴ Memorandum of the Conference of Medical Royal Colleges and their Faculties, 15 January 1979.

⁵ P 173; QQ 16, 92.

⁶ Former Parliamentary Counsel.

DECISION-MAKING FOR INCOMPETENT PATIENTS

163. As discussed in paragraphs 41-44 above, the right of a patient to refuse or consent to medical treatment depends on the patient being competent. In the case of an incompetent patient no-one has legal authority to give (or withhold) consent on the patient's behalf; legal justification is therefore required before treatment may be given.

Best interests

164. The present approach in England, made specific by a House of Lords judgment in *Re F*¹, is to allow the incompetent patient's medical carers to make decisions about treatment in the patient's "best interests".

165. Inevitably, when one individual or group seeks to make decisions about the best interests of another, questions arise as to what factors should properly be given account. The perceived quality of life of the patient is one of the more controversial factors.

166. ENABLE said that they considered it might be appropriate to withdraw treatment from a pvs patient who had "no consciousness whatsoever and no hope of recovery. In such cases it is reasonable to argue that quality of life is not poor but non-existent" (p 89). However they also expressed concern that judgments about quality of life should not lead to discrimination against disabled people. They cautioned that what seemed intolerable to one person might be acceptable to another, and that "the actual quality of a disabled person's life often depends less on their disability than on the way society treats the person" (p 89).

167. The Handicap Division of the SPUC said that "quality of life decisions made on behalf of those who are sick or disabled have no place in rigorous ethical thought...any grading of human beings according to value or worth is both repugnant and highly dangerous, since once one human life is judged worthless or expendable, all are inevitably reduced from an infinite to a relative value" (P 249).

168. The Feminist Legal Research Unit at the University of Liverpool drew attention to another potential inadequacy of the 'best interests' test. They suggested that it "does not ensure a full consideration of all the issues before a decision is reached" and that the decision could often be influenced by the interests of people other than the patient. Moreover, the decision would only be subject to open scrutiny (as by a court) if anyone disagreed with the course of action proposed (p 103).

Parens patriae jurisdiction

169. For many centuries there existed a prerogative jurisdiction whereby the Crown as *parens patriae* had both the power and the duty to protect the persons and property of those unable to do so for themselves, a category which included both minors and persons of unsound mind. So much of the *parens patriae* jurisdiction as related to minors now survives in the form of a wardship jurisdiction of the High Court, Family Division. The *parens patriae* jurisdiction relating to persons of unsound mind was removed by the combined effect of section 1 of the Mental Health Act 1959 and a Warrant under the Sign Manual dated 10 April 1956.

170. Recently, interest has been displayed in some quarters in the possibility of restoring this ancient jurisdiction, in order to provide a secure jurisprudential basis for the intervention of the court in situations of the kind with which we are now concerned. Undoubtedly, legislation would be required for this purpose. Sir Stephen Brown thought that it would be difficult to revive the jurisdiction. Moreover, from a practical point of view he considered that the existing procedure of application to the court could be developed instead (Q 287). The Official Solicitor said "it is now established beyond doubt that the *parens patriae* jurisdiction of the courts in relation to the adult mentally incompetent is in abeyance. Merely for legislation to be passed to allow for courts to

¹ [1990] 2.A.C.1. (*Mental Patient: Sterilisation*).

authorise treatment in relation to the adult mentally incompetent would not, in my opinion, cause the jurisdiction to be revived" (p 191).

171. The Law Commission said that to revive the *parens patriae* jurisdiction, even were that possible, would leave a number of questions unresolved, and that a new framework was therefore preferable (p 145).

Substituted judgment

172. In the United States the courts have developed, in place of the 'best interests' test for decision-making on behalf of incompetent patients, the 'substituted judgment' test. In 'substituted judgment' the person authorised to make a decision seeks to establish what decision the patient, if competent, would have made, by reference to any previous expression of intent by the patient or to the patient's personal values and preferences (p 60). The Centre of Medical Law and Ethics noted that such an approach was only possible where the patient "was once competent to express an intent or to have values and preferences in relation to medical care and treatment" and was of no use in cases of permanent incompetence (p 61).

173. The Centre of Medical Law and Ethics found it "disappointing" that the 'substituted judgment' test had been dismissed by English judges, and recommended that it should be preferred to the 'best interests' test (p 61). The UKCC also favoured the possible introduction of the substituted judgment test in appropriate circumstances (PP 140, 141).

174. ENABLE said that where a patient had a lifelong disability such that their wishes could not be known at all, they would favour the 'best interests' rather than 'substituted judgment' test (p 89). This must of course be so, since 'substituted judgment' is only possible where the patient holds, or has held in the past, beliefs, values or aspirations on which a judgment may be based.

Role of the family

175. The Centre of Medical Law and Ethics recommended that family members should be given some authority to make decisions for an incompetent patient (p 61). While they recognised the potential problems—disagreement among family members, conflicting interests, misjudgment of the patient's own preferences (p 60)—they suggested that family members would usually be most concerned for the patient's welfare and most familiar with the patient's own values and goals (p 59). Most US courts had vested some decision-making power in the family (p 59).

Proposals for change

176. The Law Commission have for some time been engaged in a project on decision-making for incapacitated adults. One topic of that project is medical decision-making and the Commission published a Consultation Paper in March 1993¹. We have been greatly assisted by the provisional proposals which it sets out, and by the indications which the Commissioners have kindly given us of the way in which their thinking has evolved since then. The Scottish Law Commission is also conducting a similar project² and expects to publish recommendations later in the year.

177. The Law Commission proposed that a new judicial forum be established with power to make orders approving or disapproving medical treatment for incompetent patients. This would meet a point raised by the BMA, who said that they had "been concerned for some years that the state of the law...is effectively denying treatment to certain groups of patients" (Q 109) because nobody is presently empowered to authorise treatment. The Law Commission proposed that the new forum should make orders in the best interests of the patient, taking into account

¹ The Law Commission, Consultation Paper No. 129, *Mentally Incapacitated Adults and Decision-Making: Medical Treatment and Research*.

² Scottish Law Commission, Discussion Paper No. 94, *Mentally Disabled Adults: Legal Arrangements for Managing their Welfare and Finances*.

“(1) the ascertainable past and present wishes and feelings (considered in the light of his or her understanding at the time) of the incapacitated person;

(2) whether there is an alternative to the proposed treatment, and in particular whether there is an alternative which is more conservative or which is less intrusive or restrictive;

(3) the factors which the incapacitated person might be expected to consider if able to do so, including the likely effect of the treatment on the person’s life expectancy, health, happiness, freedom and dignity, but not the interests of other people except to the extent that they have a bearing on the incapacitated person’s individual interests”.

They proposed that the approval of the judicial forum should be required for “special category” procedures such as sterilisation or operations to permit tissue donation.

178. The BMA also proposed a new procedure for decision-making in respect of medical treatment for incompetent patients. They said “the principal motive for establishing such procedures is to enable treatment rather than authorise its withdrawal” (P 30). They proposed a three-tier procedure, with a committee in each health district with “the legal authority to act on behalf of any mentally incapable adult seeking diagnosis or treatment” (P 40). At the first level, the most routine of medical decisions would be taken by the doctor, the patient and those caring for the patient. At the second level, on less straightforward, but still uncontroversial, matters a single member of the committee would be involved. The member would “ask the sort of questions that the patient would have asked had he or she been able” and would make a decision in the light of the available information. At either of these first two levels a decision could, in the event of dispute, be referred to the whole committee, which would also regularly review the decisions of its individual members. At the third level, decisions of major significance for the patient would be made by the whole committee. If they were unable to reach a decision, or if someone caring for the patient disagreed with their decision, the matter could be referred to the courts. Oversight of the local committees should be provided by the Mental Health Act Commissioners (P 41). Sir Stephen Brown said that in practical terms the BMA’s proposal had “a lot to recommend it” (Q 313). The Bio-Ethics Committee of the Newman Association considered that if such a system were adopted “the patient should have independent advocacy” by someone who reflected his or her moral and cultural traditions, and not be represented only by the Official Solicitor (pp 13,14).

179. ENABLE strongly supported proposals for new decision-making bodies for incompetent patients, as put forward by the Scottish and English Law Commissions (p 92). The Mental Health and Disability Sub-Committee of the Law Society also considered “that, in relation to incapacitated patients, complex decisions concerning medical treatment or the withdrawal of treatment should not be left solely to the medical profession, nor in some cases just to the individuals involved, but should be subject to review by a judicial authority” (p 152).

180. The RCN emphasised the importance of involving the whole health-care team, and those close to the patient, in full discussions about the care options. “If discussions are held in an open way, over a period of time it is usual for a consensus to emerge” (P 71)¹.

ADVANCE DIRECTIVES

181. As we discussed earlier, the competent patient takes part in the decision-making process about his or her medical treatment, and no action may be taken without his or her consent. The patient has a measure of autonomy in choosing between available alternatives. Advance directives are a means by which such autonomy can be extended to a situation when the patient has become incompetent, by stating in advance the types of treatment which the patient would or would not find acceptable in certain circumstances. In recent years much public interest has been shown in advance

¹ See also Q 143.

directives, with model forms being distributed from a number of sources, including for example, the Terrence Higgins Trust (THT), the VES, and Mrs Phyllis Goodheir, an independent distributor.

182. There is at present no legislation governing advance directives, and their legal status has not been specifically tested in the United Kingdom. However the courts have pronounced on the subject from time to time, in particular in the case of *Re T (Adult:Refusal of Treatment)*¹, which was discussed in the evidence of the Centre of Medical Law and Ethics (pp 57, 58) and of the THT (p 236). In that case the judges in the Court of Appeal made it clear that they considered an anticipatory refusal of treatment to be binding, provided it fulfilled certain conditions. They were that the person concerned was competent, had contemplated the situation which later arose, appreciated the consequences of refusing treatment, and was not unduly influenced by another. More recently, in the case of *Bland v Airedale NHS Trust*, Lord Goff of Chieveley said "it has been held that a patient of sound mind may, if properly informed, require that life support should be discontinued...the same principle applies where the patient's refusal to give his consent has been expressed at an earlier date, before he became unconscious or otherwise incapable of communicating it"².

183. The CPS said that if an incompetent patient had previously made an advance directive, "doctors must abide by the terms of that previous expression of intention or wish, though special care may be necessary to ensure that any prior refusal of consent to medical treatment is still properly to be regarded as applicable in the circumstances which have subsequently occurred" (p 81). The Centre of Medical Law and Ethics said that "when applicable, their [advance directives'] legal validity and binding force is now beyond question" (p 58). The Law Commission also regarded advance directives as "recognised at common law, which does not permit treatment to be provided which the patient has previously refused", provided the conditions set out by *Re T* have been met (p 144).

184. In October 1993 the High Court ruling in *Re C* was greeted by some press reports³ as confirming the status of advance directives. C, a schizophrenic patient at Broadmoor Hospital, had a gangrenous leg for which his doctors proposed amputation. C refused consent to the operation. Since the hospital trust where he was being treated refused to undertake not to operate in future should C become incompetent, an injunction was sought forbidding the amputation now or in the future. The Court held that C was competent to make a decision about the proposed treatment and that his decision should continue to be binding even should he become incompetent, and issued an injunction. While the law is obviously in a state of rapid development, the case shows a move towards judicial recognition that the choice of a patient may have prospective as well as immediate effect.

185. The Mental Health and Disability Sub-Committee of the Law Society said that many solicitors are now preparing advance directives on their clients' instructions (p 152). Widespread support for directives has also been documented by the THT (p 236) and by the Alzheimer's Disease Society (p 5). The BMA spoke of an "upsurge of public interest" (P 35). Scottish Action on Dementia (SAD) suggested that "there would not be the current interest in and demand for living wills in the United Kingdom if current codes of professional ethics were meeting patients' needs" (p 230).

186. The safeguarding of individual autonomy is widely regarded as one potential benefit of advance directives. SAD said that it is "still the case that many United Kingdom doctors do not respect patient autonomy" and that advance directives could help to redress that (p 227). The THT said that advance directives "could benefit people with HIV and AIDS by increasing their control

¹ [1992] WLR 782.

² [1993] 2 WLR 367.

³ See for example British Medical Journal 23 October 1993, 1023-24; Guardian 15 October 1993.

over their own treatment" (p 235). Other witnesses made the same point in respect of other groups of patients¹.

187. Another benefit suggested by witnesses was the comfort that patients could derive from knowing that their wishes had been clearly documented and would be taken into account. The Royal College of Nursing said "many people...are not necessarily afraid of death, but are afraid of the manner of death...For them writing a living will gives them comfort, not least because they feel they are able to continue to have control and autonomy in their lives, even at a time when they can no longer exercise that autonomy directly" (P 73)².

188. The preparation of an advance directive can provide a valuable opportunity for dialogue between doctor and patient. This advantage was widely recognised³. The BMA urged that such dialogue should be regarded not only as a potential benefit of the preparation of an advance directive, but as a necessary part of the process. "Any patients who wish to draft advance directives should ensure that they are well informed and do so with the benefit of medical advice. It is also recommended that this initiative should become part of a continuing dialogue between doctor and patient so that both are fully apprised of the other's opinion" (P 35).

189. The BMA welcomes advance directives as an aid to doctors, in acquainting them with their patient's views as to the kinds of treatment the patient might have declined if competent (P 30)⁴. This could be of particular value when the patient is otherwise unknown to the doctor. The Medical Ethics Committee of the Order of Christian Unity observed that with greater mobility relatively few patients any longer had a lasting relationship with a family doctor who would thus be acquainted with their views and preferences, and that in these circumstances "advance directives may help a physician to treat in accordance with the patient's wishes" (p 196). The Patients Association said that "a general indication of a patient's wishes, made and recorded formally, should relieve his doctor of the responsibility of acting without consent" (p 208). The RCN said that a directive "is clearly a great help to the health care team" (P 73). Other witnesses also acknowledged the assistance that advance directives could give⁵.

190. Another advantage suggested by witnesses was the relief that an advance directive could provide to the family of an incompetent patient. Relatives are often consulted about the treatment of an incompetent patient, and very often find it difficult or distressing to contribute to decision-making. The knowledge that they could be guided by the previously expressed wishes of the patient could relieve them of some of that burden⁶. THT suggested further that, in the case of AIDS patients, an advance directive "might help to resolve disputes about a patient's medical treatment which, sadly, arise on occasion between a patient's family on the one hand, and his or her partner, on the other" (p 235).

191. Equally, however, witnesses discussed a number of difficulties which advance directives can pose. The difficulty of expressing unambiguously one's intentions in as yet unknown circumstances was raised by the National Hospice Council. They said that "the precise interpretation of an advance directive would always be open to doubt" (P 208)⁷. The SPUC suggested that where this was so the advance directive would simply add to the difficulty which the doctor faced in reaching a clinical judgment (P 239).

¹ See for example pp 5, 31, 219.

² For similar views see for example pp 5, 152, 226, 235.

³ See for example P 30; pp 5, 114, 226, 235.

⁴ However, for further discussion of the BMA's position on advance directives, see below.

⁵ See for example PP 2, 110, 183, 187; QQ 58, 125, 554; pp 67, 196, 219.

⁶ See for example pp 5, 226.

⁷ For similar views see for example P 183; p 219; ME 88, p 9; ME 125, p 13;

192. The danger of misdiagnosis was also raised¹. CARE pointed out that “the event chosen to trigger the execution of a living will, often requires the attending doctor to confirm that there is no hope of recovery...However, a prognosis can only ever be the best possible guess...There are many instances of incorrect diagnoses and prognoses the effects of which cannot be corrected once the patient is dead” (p 46).

193. The impossibility of patients accurately predicting the circumstances in which they might find themselves was also mentioned. HOPE said “no-one could foresee all future possibilities” (P 110). The Joint Ethico-Medical Committee of the Catholic Union of Great Britain and the Guild of Catholic Doctors said “advance directives can never reach the high standards of informed consent which are currently required in medical practice” (p 125)².

194. Another difficulty raised was the fact that it is hard to predict one’s feelings in different circumstances. In particular a situation which might in prospect seem unbearable might in the event have its own meaning and value. CARE said “disabled individuals are commonly more satisfied with their life than able-bodied people would expect to be with the same disability. The healthy do not choose in the same way as the sick” (p 45)³.

195. Medical circumstances may change between the time of execution of an advance directive and the time at which it may become operative. New treatments may become available, or existing treatments be improved and become less burdensome. Patients might have chosen differently had they known of such progress at the time of making an advance directive⁴.

196. CARE said that “it would be bizarre in the extreme to require a skilled, professional doctor to adhere to the stipulations of a living will which did not accord with his/her expert opinion of what would be in the best interests of the patient’s health” (p 45). Dr David Cook said that to make advance directives binding “would gravely undermine the professional expertise and judgment of doctors. It would make doctors nothing more than slaves of society” (P 172).

197. The Christian Medical Fellowship said that “advance directives may hinder communication rather than help it. Where there is some possibility of communication with a patient, but it is difficult, doctors may be tempted to rely on the directive rather than make the effort to communicate with the patient” (p 67)⁵.

198. The point at which an advance directive should take effect is likely to be difficult to determine. CARE said “the implementation of a living will requires a clearly identifiable event which causes the requirements specified in the document to be acted upon...it may be no easy matter to reach agreement with all concerned that a living will should become operative” (p 45)⁶.

199. The danger that vulnerable people would be pressurised into signing advance directives was mentioned⁷. The Home Office suggested that the potential for abuse was great, that directives might be written “under false pretences or improper pressure” and that the practical difficulties of regulation were significant (P 19).

200. Some witnesses feared that advance directives were a stalking horse for euthanasia⁸. The Medical Ethics Committee of the Order of Christian Unity said “the strong support given to advance directives by the VES is, in our view, reason enough to reject them on the grounds that

¹ See for example PP 110, 285; p 67.

² For similar views see also QQ 58, 663; pp 25, 227, 263.

³ For similar views see also PP 35, 110, 239; QQ 125, 305, 554; pp 67, 196.

⁴ See for example PP 208, 239; Q 554; pp 45, 67, 219, 227, 285.

⁵ For a similar view see also P 111.

⁶ For similar views see for example P 110; p 67.

⁷ See for example PP 183, 188, 208; p 46, 114, 198, 219.

⁸ See for example PP 183, 188; pp 46, 67, 73, 264.

they may open a door to voluntary euthanasia" (p 196). HOPE suggested that the refusal of treatment could lead to greater suffering and that "it would soon be argued that this mode of dying was not 'compassionate' and that a lethal injection should rather be given...we are concerned that legalised advance directives would sooner or later lead to euthanasia" (P 111). This concern was also expressed by some of the members of the public who wrote to us¹. On the other hand the BMA perceived "a significant ethical and legal difference between the concept of an advance directive and the issue of euthanasia" (P 34). Other witnesses also felt that the two issues should and could be considered separately². Lord Allen of Abbeydale denied that his private member's bill³ was intended to legalise euthanasia. Although his bill was adapted from a draft prepared by the VES, he was not a member of the Society and did not advocate euthanasia (p 282).

201. Professor Peter Millard⁴ suggested that the widespread use of advance directives could lead to an excess of medical zeal, since doctors might feel obliged to use all possible means to maintain the lives of patients who did not have advance directives, even where early death was inevitable. He said that overtreatment in these circumstances occurred in the United States of America and in Canada (p 188). On the other hand the BMA suggested that if advance directives were legally enforceable "doctors will feel uneasy about their authority to act in an acute clinical situation" if they were not certain that they had a patient's express consent to treatment (Q 95).

202. The BMA discussed the difficulties to which advance directives could give rise in cases where the doctor had conscientious objection to the course of action requested. They said that in raising this issue they hoped "to reduce the arbitrariness of medical response to which patients are now subject". Their advice was that any doctor anticipating a difficulty of conscience over an advance directive should inform the patient at the time the directive was drawn up, so that the patient could either transfer to another practitioner or reconsider the terms of the directive. They said that it was "not ethically acceptable for a doctor simply to put an advance directive on file, without discussion and with the expectation of claiming conscientious objection when the time comes" (P 37). The SPUC also considered the matter of conscientious objection. They cited the operation of the Abortion Act 1967 as evidence that a "conscience clause" would not work effectively or prevent discrimination against objectors. They also opposed any requirement that a conscientious objector should refer the patient to another doctor, since "Ethically, such a referral could make one as culpable as if one had performed the act oneself" (P 239).

203. The organisation Doctors Who Respect Human Life questioned whether in practice advance directives would have much effect. They cited a survey which suggested that there was no significant difference in psychological wellbeing, quality of life or medical treatment between patients with or without advance directives. They also reported one doctor's comment that although many directives had been signed, patients rarely drew attention to them (p 86).

204. The THT emphasised the need for an advance directive to be "in clear and unambiguous language accessible to the general lay public" (p 237). The VESS stressed that any advance directive should be sufficiently "simple and empathetic" in style to be easily used and understood by doctors and patients (p 266). The THT recommended that provision should be made for revocation of directives; that whilst a model form might be included in any legislation no single form should be prescribed; and that provision should be made for a directive to cover a wide range of possibilities, including requests for all reasonable medical treatment to be given (p 237). VESS also made a number of practical suggestions about the operation of advance directives, including a system of registration and the carrying of a card to indicate that a directive had been completed (p 267).

¹ See Appendix 2.

² See for example pp 2, 5.

³ See paragraph 207 below.

⁴ Eleanor Peel Professor of Geriatric Medicine, St. George's Hospital Medical School, University of London.

205. Many witnesses considered the question whether, in the light of the potential advantages and disadvantages of advance directives, there should be legislation to formalise their status. In this connection different witnesses used the expression “legally binding” in different ways. It could mean that the doctor was obliged to act in accordance with a directive regardless of circumstances; or that the doctor was obliged to comply subject to certain conditions; or that the doctor would be secure from liability if he or she complied. The VES argued that there should be legislation. They said that a doctor must observe the terms of a directive, “otherwise the patient has no autonomy” (Q 199) and that legal sanctions should apply to a doctor who failed to comply (Q 200). The Alzheimer’s Disease Society also favoured legislation since “unless they have legal status, they will be valueless as an expression of the patient’s will. There seems little purpose in having directives which can ultimately be ignored by doctors” (p 6). Professor Charles Fletcher also considered that “some legal sanction should be available to ensure that the patient’s wishes prevail” (p 111). Professor Dworkin suggested that where the circumstances were as anticipated by the patient a doctor should be obliged to comply with the terms of a directive, even if it ran counter to the representations of those nearest to the patient, or to transfer the patient to another practitioner. Where the circumstances were not as anticipated by the patient, decisions would depend on the clinical judgment and good faith of the doctor (QQ 478-82).

206. The Mental Health and Disability Sub-Committee of the Law Society said “it is important that the law establishes clear rights for competent patients to decide what treatment they will accept, and when, even after they lose capacity” (p 153).

207. Others suggested that less far-reaching legislation would be appropriate, simply to ensure that the position of doctors complying with advance directives was safeguarded. Such was the purpose of Lord Allen of Abbeydale’s private member’s bill¹. Lord Allen described the Bill’s effect: “if an individual when of sound mind makes an advance directive about the withholding or withdrawal of life-sustaining treatment in the event of that individual suffering from one or more of certain specified conditions without hope of recovery and being no longer able to take decisions, then a doctor, although not obliged to comply with such a directive, is not committing a criminal offence (or rendering himself liable to disciplinary proceedings for unprofessional conduct) if when the time comes he does comply” (p 3). Although the BMA had suggested that legislation was unnecessary since there was already so strong a presumption that advance directives should, wherever possible, be complied with (P 30), Lord Allen said that the remaining degree of uncertainty still troubled some doctors, who “would feel happier if there were some positive determination” (p 283).

208. The Law Commission proposed that “legislation should provide for the scope and legal effect of anticipatory decisions” or advance directives, which “should be as effective as the contemporaneous decision of the patient would be in the circumstances to which it is applicable”². They suggested that legislation should provide for the witnessing of directives, and should make it an offence to forge, conceal, alter or destroy another person’s directive without their consent.

209. The Centre of Medical Law and Ethics said that there was “a strong case” for legislation on advance directives, to remove “any residual uncertainty about the common law” and to provide for matters such as the form, witnessing and revocation of directives. Legislation could also clarify the position of a doctor who, not knowing of the existence of a directive or believing it to be inapplicable, gave treatment against a patient’s anticipatory wish (p 58).

210. The THT recognised that there would be “great difficulty in drafting legislation which would clearly define the circumstances in which a living will is to take effect or to have binding force” (p 237). However they considered that this “need not present an obstacle to developing a

¹ Medical Treatment (Advance Directives) Bill [H.L.], HL Bill 73, Session 1992-93.

² The Law Commission, Consultation Paper No.129, *Mentally Incapacitated Adults and Decision-Making: Medical Treatment and Research*.

form of living will provided that doctors were in practice prepared to give effect to the wishes expressed" (p 236).

211. Jonathan Montgomery¹ has drawn attention to a particular danger of legislating to make advance directives binding. He points out that if a directive is to be legally binding then the circumstances in which it is to take effect must be precisely defined. "However, the more precisely that the events are described, the more likely it is that the actual scenario would be different and that the declaration would be held to be inapplicable. Thus, the practical effect of increasing the force given to directives might be to reduce the number which would be effective"².

212. Some witnesses considered that the difficulties to which advance directives could give rise were such that there should be no legislation on the subject³. The BMA does not favour legislation (PP 30, 35). It said that where an advance directive was sufficiently clear and well-informed, and where the prevailing circumstances were those which the patient had previously considered, "doctors should regard the patient's wish as determinative" but that it should be possible for a directive to be overridden by clinical judgment (P 38)⁴. Dr Stuart Horner said for the Association "an advance directive must be respected as a valid expression of the patient's wishes but inevitably the doctor will have to take other things into account...we are concerned that the introduction of legislation may actually restrict the freedom of doctors to do what their patients wish" (Q 82). Dr Twycross, speaking for HOPE, drew our attention to a survey in Canada which suggested that many patients would prefer their doctors to have some room for professional discretion in considering the instruction of advance directives (Q 275, and note to Q 283).

213. The RCN considered that the time is not right for legislation at present. They encouraged their members always to give due weight to the views of patients, however expressed (Q 171), but were afraid that giving greater legal status to advance directives would give rise to "defensive practice" (Q 170). They said that more experience was needed of how advance directives could assist decision-making, and more openness about the ethical dilemmas surrounding care of patients at the end of their lives, before legislation might be appropriate (P 73).

214. SAD drew our attention to some of the difficulties encountered in the United States of America in legislating for advance directives (or living wills, as they are more commonly known there) (pp 228-9).

215. As part of their consultation process on mentally incapacitated adults and decision-making, the Law Commission have published proposals for legislation on advance directives⁵. Their proposals envisage that doctors should not be bound to give treatments requested by patients unless that accords with their professional judgment, but that a refusal of treatment expressed in advance should carry as much weight as refusal by a currently competent patient (p 144).

PROXY DECISION-MAKERS

216. In response to the conceptual difficulties of "best interests", and perhaps also to the note of paternalism which some commentators claim to detect in it, an alternative has been developed whereby a person is appointed to arrive at a decision which corresponds as closely as possible to the decision which the patient would have made if he or she had been in a condition to make it. This is the solution which the courts of the United States have preferred. Strictly applied, the doctrine differs fundamentally from the approach to "best interests". The latter looks from outside at what is seen objectively to be for the best. In contrast, the surrogate or proxy works from within the situation, and gives effect to the ideal of patient autonomy by making a substituted choice on the

¹ Lecturer in Law at the University of Southampton.

² Jonathan Montgomery, "Power over death: the final sting", in R. Lee and D. Morgan (eds), *Deathrites: Law and Ethics at the End of Life* (Routledge, 1993).

³ See for example P 112.

⁴ For a similar view see also PP 3, 183.

⁵ The Law Commission, *Medical Treatment and Research*, Consultation Paper No. 129, para.3.8.

patient's behalf: a choice which will not necessarily be the one which the generality of people would regard as "best". If the competent patient is free to choose what objectively appears the worse option, and to have his choice respected, then logically the same must be the case where someone is choosing on his behalf.

217. Surrogate decision-makers are of two kinds: those appointed by the patient in advance of becoming incompetent, and those (whether a relative, the medical team, a judicial tribunal or a person selected by the court) who either choose themselves or are chosen by the court when the time for a decision arrives.

218. The appointment by a patient of someone who would take responsibility for decision-making in the event of the patient becoming incompetent has not yet been tested in the courts and it is thought that such a procedure is not covered by any existing legislation (p 236). The principle of a patient appointing a proxy was widely welcomed as a means of taking account of the patient's known wishes and beliefs, while also considering the circumstances which actually prevail¹. The BMA said that they encourage patients who are "likely to face mental degeneration" to consider appointing a proxy (P 30). One advantage of appointing a proxy is that he or she can take decisions in the light of the specific circumstances which arise (P 30). The Mental Health and Disability Sub-Committee of the Law Society favoured a combination of advance directives and proxy decision-makers. "This combination would have the advantage of setting down the person's wishes on a legal document, while also appointing someone to ensure those wishes are enforced, as well as being able to make related decisions which may not have been clearly specified in the advance directive" (p 152). SAD favoured the same combination. "People should be encouraged to set up a durable power of attorney for health care and the attorney appointed would then state the patient's wishes with regard to life-sustaining technologies. If the patient so desires, he or she could prepare an instruction directive...This, however, would remain as a confidential document for the attorney for health care and would not be given to doctors" (p 229). SAD suggested that proxies "have the advantage in that they are more flexible and more likely to be available when needed" than advance directives (p 230).

219. Some possible disadvantages of proxies are that they may act mischievously, or their views may conflict with wishes set out in an advance directive, and a number of witnesses thought that greater consideration should be given to such potential problems before the appointment of proxies became more widespread². The BMA thought that it would be possible to establish a procedure to resolve such difficulties (P 30).

220. In the USA "the current trend is towards proxy empowerment with the living will as advisory" (p 271)³. A similar trend is apparent in Canada (p 59) and in Australia; in South Australia for example a recent parliamentary enquiry recommended repealing the 1983 legislation on advance directives "and replacing it with legislation establishing the means for appointing a specific enduring power of attorney for medical treatment" (p 240). In Victoria legislation was enacted in 1989 and 1990 after a parliamentary enquiry, providing for the appointment of "patient agents". Advance directives were not given legal status because they were not seen as a reliable way of establishing the wishes of a dying patient in a particular situation (p 242). The legislation in Victoria also provided for oversight and review of the decisions of proxies by a Guardianship Board (p 243).

221. The Law Commission proposed that their suggested new judicial forum⁴ should be able to appoint a medical treatment proxy in cases where it found that an order on a single issue would

¹ See for example pp 46, 58, 219, 229, 271.

² See for example pp 46, 220.

³ See also p 59.

⁴ See paragraph 177 above.

"not be sufficient to benefit the incapacitated person"¹. They also proposed that an individual should be able to execute an enduring power of attorney, so that the person named could give or refuse consent to treatment on the individual's behalf should the individual become incompetent to do so. They proposed that both a medical treatment proxy and a medical treatment attorney should be required to take into account the same factors as would be considered by the judicial forum².

HEALTH-CARE TEAMS

222. The importance of all health-care professionals in caring for patients was emphasised by witnesses³. In particular the RCN emphasised that not only doctors faced ethical dilemmas. Nurses "have an autonomous duty towards their patients" and "make many independent decisions about care". The RCN suggested therefore that it was more appropriate to speak of health care ethics than simply medical ethics. They also pointed out that from their close and sustained contact with patients, nurses "often have different perspectives on a particular case from their medical colleagues" and it was therefore important that they should be involved in the decision-making process (P 70)⁴. The Nurses' Christian Fellowship made a similar point (p 190).

223. The UKCC regretted that the special contribution which nurses could make to decision-making, because of their close relationships with patients, was often overlooked by other practitioners (Q 409). This was particularly so "in intensive care units and acute medical and surgical situations", though in palliative care and care of the elderly the situation was improving (Q 410).

A NATIONAL ETHICS COMMITTEE

224. The Royal College of Midwives suggested that there was a case for a permanent, national forum to debate and regulate issues of health-care ethics and that the need for such a body would increase as questions of rationing arose (p 216).

TRAINING IN HEALTH CARE ETHICS

225. Health care professionals are frequently faced with the need to make difficult ethical decisions. The British Geriatrics Society said "medical ethics training should be enhanced". They also said that a recent instruction from the GMC to medical schools to introduce the subject in undergraduate training should result in improvement (p 26). The RCN said that the training which nurses received to assist them in dealing with ethical problems was improving (Q 186). The UKCC also said that there was "a significant trend to address these matters in programmes of education leading to registration" and also that the Council would be using its new powers to be "more prescriptive" about the content of training programmes (Q 421).

CARDIOPULMONARY RESUSCITATION

226. Although not strictly within our terms of reference, decisions about when to implement cardiopulmonary resuscitation (CPR), and when not, raise similar ethical questions about the point at which it is appropriate to cease efforts to prolong life, and about the best interests of the patient. CPR can be attempted on any patient whose cardiac or respiratory functions cease and in many cases will result in a welcome and worthwhile prolongation of meaningful life. In some circumstances though CPR could represent a traumatic and undignified interruption of the natural process of dying. As the BMA says, "It is therefore essential to identify patients for whom cardiopulmonary arrest represents a terminal event in their illness and in whom CPR is inappropriate" (P 39). Identification of such patients results in do-not-resuscitate (DNR) orders being made.

¹ The Law Commission, Consultation Paper No. 129, *Mentally Incapacitated Adults and Decision-Making: Medical Treatment and Research*.

² See paragraph 177 above.

³ See for example Q 103; p 65.

⁴ See also QQ 134, 135, 262.

227. The BMA and RCN, in association with the Resuscitation Council (UK), have issued guidelines to practitioners on the subject of DNR orders (PP 39,40). These state that responsibility for a DNR order rests with the consultant in charge of the patient's care, and that a DNR order might be considered in one of three circumstances: "where the patient's condition indicates that effective CPR is unlikely to be successful; where CPR is not in accord with the recorded, sustained wishes of the patient who is mentally competent; where successful CPR is likely to be followed by a length and quality of life which would not be acceptable to the patient" (P 39). The guidelines emphasise that it is desirable for the decision to be made in discussion with the whole health-care team, and with the patient where appropriate, and that the reasons for the decision should be thoroughly recorded (P 40)¹.

228. VESS drew our attention to the development in the USA of Pre-Hospital Do-Not-Resuscitate Orders. Several states have adopted either by statute or regulation a "means of identification of individuals' wishes regarding life-sustaining procedures or do-not-resuscitate to be met when emergency personnel are called", so that CPR is not automatically given by an ambulance crew to a patient in a critical state (p 269).

SELECTIVE TREATMENT OF INFANTS

229. Although not specifically raised by our terms of reference, medical practice in respect of infants² cannot be excluded from any consideration of decision-making about the withholding or withdrawing of medical treatment. Dilemmas arise for example where infants are born with major abnormalities, particularly of the central nervous system, and it may be thought compassionate not to prolong life by means of all available medical resources. There is a need to weigh the burdens to the infant of continuing treatment against the likely benefits. The British Paediatric Association observed also that "the demand for neonatal intensive care has always been slightly greater than the available care. There are therefore various pressures on neonatal paediatricians to select which infants receive high-technology life support" (p 34).

230. The Association drew our attention (p 35) to a survey which reported that in one London hospital in the 1980s 30 per cent of deaths in neonatal intensive care followed withdrawal of treatment. In each case the decision had been discussed first among the medical and nursing personnel and then with the parents, and withdrawal only followed where all were in agreement. The infants concerned were extremely premature, had severe congenital abnormalities or severe acquired neurological damage.

231. The Association was opposed to any suggestion that such decisions should be regularly reviewed by the courts. They considered that "such a requirement would greatly increase the workload of the courts and of neonatal paediatricians, and would be unlikely to diminish parental anguish or neonatal suffering" (p 35). They cautioned therefore that any new legal framework for decision-making in respect of incompetent patients should not extend to infants. They considered however that practitioners, parents and the courts could be assisted by a code of practice on the selective non-treatment of infants, so were working to produce such a code (p 35).

NEXT OF KIN

232. As the THT pointed out, hospital forms often require patients to give details of their "next of kin", which "does suggest to a patient that he or she is supposed to record the name of a family member". Yet in a survey in which the Trust participated "while almost all of those asked said they would consider appointing a health care proxy, most would not appoint a family member" (p 236). The Centre of Medical Law and Ethics also recognised this difficulty, and suggested that 'family' or 'next of kin' should be interpreted as "the individual most closely associated with the patient" (p 60).

¹ See also P 72.

² We use this term loosely to include also neonates, that is, babies in the first four weeks of life.

PART 3 OPINION OF THE COMMITTEE

PATIENT'S CONSENT

233. The concept of patient's informed consent¹ is nowadays at the heart of the relationship between doctor and patient, and governs decisions about medical treatment. As well as giving appropriate weight to the wishes of the individual the issue of consent, if properly approached, encourages full and open communication between doctor and patient in a consultative partnership. This is much to be welcomed.

234. We strongly endorse the right of the competent patient to refuse consent to any medical treatment, for whatever reason. The doctor must ensure that the patient understands the likely consequences of such refusal, and the reasons for proposing a particular treatment, but no member of the health-care team may overrule the patient's decision.

235. In some exceptional circumstances there may be a public interest in the outcome of a treatment decision relating to a competent patient which is thought to surpass the interest of the individual. Such a decision must be taken by the High Court, and may not be taken by the health-care team. We do not consider it appropriate to comment on the specific facts of the case in *Re S*, to which witnesses drew our attention². But we urge that, if an individual refusal of treatment by a competent patient is overruled by the Court, full reasons should be given. Only thus can patients be assured that their right to refuse consent to treatment is protected, and that they will not be subjected to medical procedures against their will.

VOLUNTARY EUTHANASIA

236. The right to refuse medical treatment is far removed from the right to request assistance in dying. We spent a long time considering the very strongly held and sincerely expressed views of those witnesses who advocated voluntary euthanasia³. Many of us have had experience of relatives or friends whose dying days or weeks were less than peaceful or uplifting, or whose final stages of life were so disfigured that the loved one seemed already lost to us, or who were simply weary of life. Our thinking must inevitably be coloured by such experience. The accounts we received from individual members of the public about such experiences were particularly moving, as were the letters from those who themselves longed for the release of an early death. Our thinking must also be coloured by the wish of every individual for a peaceful and easy death, without prolonged suffering, and by a reluctance to contemplate the possibility of severe dementia or dependence. We gave much thought too to Professor Dworkin's opinion that, for those without religious belief, the individual is best able to decide what manner of death is fitting to the life which has been lived.

237. Ultimately, however, we do not believe that these arguments are sufficient reason to weaken society's prohibition of intentional killing. That prohibition is the cornerstone of law and of social relationships. It protects each one of us impartially, embodying the belief that all are equal. We do not wish that protection to be diminished and we therefore recommend that there should be no change in the law to permit euthanasia. We acknowledge that there are individual cases in which euthanasia may be seen by some to be appropriate. But individual cases cannot reasonably establish the foundation of a policy which would have such serious and widespread repercussions. Moreover dying is not only a personal or individual affair. The death of a person affects the lives of others, often in ways and to an extent which cannot be foreseen. We believe that the issue of euthanasia is one in which the interest of the individual cannot be separated from the interest of society as a whole.

¹ See paragraphs 40-49 above.

² See paragraphs 46 and 47 above.

³ See in particular paragraphs 92-94, 98-100, 102, 105, 109 and 111 above.

238. One reason for this conclusion is that we do not think it possible to set secure limits on voluntary euthanasia. Some witnesses told us that to legalise voluntary euthanasia was a discrete step which need have no other consequences. But as we said in our introduction, issues of life and death do not lend themselves to clear definition, and without that it would not be possible to frame adequate safeguards against non-voluntary euthanasia if voluntary euthanasia were to be legalised. It would be next to impossible to ensure that all acts of euthanasia were truly voluntary, and that any liberalisation of the law was not abused. Moreover to create an exception to the general prohibition of intentional killing would inevitably open the way to its further erosion whether by design, by inadvertence, or by the human tendency to test the limits of any regulation. These dangers are such that we believe that any decriminalisation of voluntary euthanasia would give rise to more, and more grave, problems than those it sought to address. Fear of what some witnesses referred to as a "slippery slope" could in itself be damaging.

239. We are also concerned that vulnerable people—the elderly, lonely, sick or distressed—would feel pressure, whether real or imagined, to request early death. We accept that, for the most part, requests resulting from such pressure or from remediable depressive illness would be identified as such by doctors and managed appropriately. Nevertheless we believe that the message which society sends to vulnerable and disadvantaged people should not, however obliquely, encourage them to seek death, but should assure them of our care and support in life.

240. Some of those who advocated voluntary euthanasia did so because they feared that lives were being prolonged by aggressive medical treatment beyond the point at which the individual felt that continued life was no longer a benefit but a burden. But, in the light of the consensus which is steadily emerging over the circumstances in which life-prolonging treatment may be withdrawn or not initiated, we consider that such fears may increasingly be allayed. We welcome moves¹ by the medical professional bodies to ensure more senior oversight of practice in casualty departments, as a step towards discouraging inappropriately aggressive treatment by less experienced practitioners.

241. Furthermore, there is good evidence that, through the outstanding achievements of those who work in the field of palliative care², the pain and distress of terminal illness can be adequately relieved in the vast majority of cases. Such care is available not only within hospices: thanks to the increasing dissemination of best practice by means of home-care teams and training for general practitioners, palliative care is becoming more widely available in the health service, in hospitals and in the community, although much remains to be done. With the necessary political will such care could be made available to all who could benefit from it. We strongly commend the development and growth of palliative care services.

DOUBLE EFFECT

242. In the small and diminishing number of cases in which pain and distress cannot be satisfactorily controlled, we are satisfied that the professional judgment of the health-care team can be exercised to enable increasing doses of medication (whether of analgesics or sedatives) to be given in order to provide relief, even if this shortens life. The adequate relief of pain and suffering in terminally ill patients depends on doctors being able to do all that is necessary and possible. In many cases this will mean the use of opiates or sedative drugs in increasing doses. In some cases patients may in consequence die sooner than they would otherwise have done but this is not in our view a reason for withholding treatment that would give relief, as long as the doctor acts in accordance with responsible medical practice with the objective of relieving pain or distress, and with no intention to kill.

¹ See for example the discussion document of the British Association of Accident and Emergency Medicine, March 1991. Since then the Churchill John Radcliffe Hospital, Oxford, has introduced 24-hour shift working by accident and emergency consultants (press reports 31 December 1993).

² See paragraphs 136 to 145 above.

243. Some witnesses suggested that the double effect¹ of some therapeutic drugs when given in large doses was being used as a cloak for what in effect amounted to widespread euthanasia, and suggested that this implied medical hypocrisy. We reject that charge while acknowledging that the doctor's intention, and evaluation of the pain and distress suffered by the patient, are of crucial significance in judging double effect. If this intention is the relief of severe pain or distress, and the treatment given is appropriate to that end, then the possible double effect should be no obstacle to such treatment being given. Some may suggest that intention is not readily ascertainable. But juries are asked every day to assess intention in all sorts of cases, and could do so in respect of double effect if in a particular instance there was any reason to suspect that the doctor's primary intention was to kill the patient rather than to relieve pain and suffering. They would no doubt consider the actions of the doctor, how they compared with usual medical practice directed towards the relief of pain and distress, and all the circumstances of the case. We have confidence in the ability of the medical profession to discern when the administration of drugs has been inappropriate or excessive. An additional safeguard is that increased emphasis on team working makes it improbable that doctors could deliberately and recklessly shorten the lives of their patients without their actions arousing suspicion.

244. We would add that the effects of opiates (the drugs most commonly involved in double effect) and of some other pain-relieving and sedative drugs are so uncertain that the outcome of a particular dose can never be predicted with total confidence. The body weight, metabolism, habituation and general condition of the individual patient all affect the response. There have been cases where an error in dispensing resulted in the administration of a dose which seemed likely to be lethal, yet the patient flourished. A doctor called to testify in the case of Dr Bodkin Adams asserted that a particular dose must certainly kill, only to be told that the patient had previously been given that dose and had survived. The primary effect (relief of pain and distress) can be predicted with reasonable confidence but there can be no certainty that the secondary effect (shortening of life) will result. Decisions about dosage are not easy, but the practice of medicine is all about the weighing of risks and benefits.

DECISION-MAKING FOR INCOMPETENT PATIENTS

245. The need for society to offer special protection to those who are vulnerable means that special provision should be made for medical decision-making in respect of incompetent patients. We therefore support the proposal of the Law Commission that a new judicial forum should be established with power to authorise the commencement, withholding or withdrawal of treatment where this is in the patient's best interests. Such a forum would have power to choose between alternatives, rather than simply to declare that a proposed course of action would or would not be lawful, as the courts do at present. We do not envisage that application to the forum would be a routine event: in most cases consultation among the health-care team and the family or other people closest to the patient will result in agreement on an appropriate course. But in the event of dispute as to what is in the patient's best interests, or doubt as to the legality of what is proposed, recourse to an authoritative forum would be of advantage. We also support the proposal of the Law Commission that certain "special category" procedures should always require the authority of the forum.

246. We understand that the Law Commission are likely to recommend that the new jurisdiction should be exercised by a reconstructed and enlarged Court of Protection, with nominated judges of the High Court and nominated circuit judges and district judges. The court would have power to appoint experts to give advice. We are not, of course, acquainted with all the details of the recommendations which the Law Commission will make. We should not, therefore, be regarded as endorsing in advance every aspect of their proposals. However in broad terms we support the creation of a new court along the lines which we understand them to be likely to propose, subject to certain qualifications set out below.

¹ See paragraphs 22 and 73 to 79 above.

247. We were initially strongly attracted by the idea of local tribunals comprising legal, medical and lay members to fulfil the functions of the new forum for medical decision-making. We felt that a forum so constituted would command greater confidence and would be more accessible to those who had recourse to it, in particular the family or friends of the patient. However we recognise that the Law Commission's intention is that a new court should discharge other functions in respect of decision-making for incompetent people, not only decisions about medical treatment. Those other functions lie outside our terms of reference. But we acknowledge that it would not be practical or desirable to establish two separate systems of decision-making, one for medical matters and another for dealing with, say, an incompetent person's financial affairs. Indeed it would no doubt sometimes be difficult to distinguish between different types of decision, or to separate one element of a person's affairs from others.

248. We regret however that an entirely judicial forum will not have the same degree of medical or lay input as a tribunal system would permit. We recommend therefore that some mechanism should be adopted whereby the new court will make full use of appropriate independent medical and ethical advice. We also recommend that the new court should be locally based and that its procedures should be as informal and accessible as possible. It should be enabled to deal promptly with emergency applications.

249. We recognise that the range of decisions which the new court will be required to take will be wide, and that some minor matters can appropriately be dealt with at quite a low level. But the type of life or death decision which is the subject of our report should be considered only by judges of appropriate status and experience. In addition to provision for appeal in individual cases we recommend that there should also be provision for monitoring decisions of the court to ensure consistency of ethical standards and direction. We recognise that other considerations may make it desirable that, at least in some cases, the proceedings of the court take place in private. Wherever possible, however, we would recommend public hearings. In any event the judgments of the court should be published.

250. In this connection we note that some witnesses suggested that use of the term "next of kin" in a medical or legal setting was misleading, often being interpreted by patients as requiring them to name their spouse or nearest blood relative when they might prefer to specify a partner or friend. Since the object is surely to identify the individual most closely associated with the patient, we recommend that the new legal forum, and the health-care professions, should adopt an expression more in keeping with current social realities.

TREATMENT-LIMITING DECISIONS

251. The issue of treatment-limiting decisions¹ is crucial to many of the concerns which our witnesses raised with us. For most practical purposes we do not discern any significant ethical difference between those decisions which involve discontinuing a treatment already begun and those which involve not starting a treatment. To make such a distinction could result in patients being subjected to the continuation of unnecessary and burdensome procedures simply because they had been started previously; or it could restrict a doctor's freedom to do everything possible for the patient in an emergency or when diagnosis is uncertain. We do not therefore distinguish between withholding and withdrawal of treatment, in our discussion of treatment-limiting decisions. However, we acknowledge that, in the case of neonates particularly, the withdrawal of treatment becomes harder as time passes, as more love and commitment are invested in the child as an individual.

252. All our witnesses agreed that there is a point at which the duty to try to save a patient's life is exhausted, and at which continued treatment may be inappropriate. But this is not a point which can be readily defined, since it must be identified in the light of each patient's individual condition and circumstances. Obviously it is inappropriate to give treatment which is futile in the

¹ See paragraphs 50 to 59 above.

sense that it fails to achieve the hoped for physical result. Indeed to continue a treatment in such circumstances could be irresponsible. A decision not to do so will rarely be controversial.

253. In other cases, a decision to limit treatment may depend on the balance between the burdens which the treatment will impose and the benefits which it is likely to produce. Competent patients can often, with medical advice and after full discussion, make such decisions themselves, perhaps for example foregoing the possibility of a few extra weeks of life because the possible side-effects of the proposed treatment might necessitate being in hospital rather than at home. Such a decision is made on the basis of the quality rather than the length of life, but few would dispute the right of the patient to choose in that way.

254. Controversy arises when treatment-limiting decisions based on the balance of burdens and benefits must be made in respect of incompetent patients. The spectre of one individual judging the quality of life of another gives rise to potent fears. But such decisions, however difficult, must be made if incompetent patients are not to be subjected to the aggressive over-treatment to which competent patients would rightly object.

255. Treatment-limiting decisions in respect of an incompetent patient should be taken jointly by all those involved in his or her care, including the entire health-care team and the family or other people closest to the patient. Their guiding principle should be that a treatment may be judged inappropriate if it will add nothing to the patient's well-being as a person. In most cases full discussion will ultimately lead to agreement on what treatment is appropriate or inappropriate. Where agreement cannot be reached after adequate discussion and time for reflection, provision should be made for a party to the decision-making to apply for a decision from the new forum which we have recommended¹.

256. Some people may suggest that clearer general guidance is needed as to the circumstances in which treatment may be judged inappropriate. But we are not satisfied that this is either possible or desirable. Such a judgment must be made in relation to the condition, circumstances and values of the individual patient. Such matters cannot be defined or legislated for and consensus must be developed on a case-by-case basis, inching forward as best we can. For these reasons we do not favour legislation on the lines of the bill presented by Lord Alport. We are confident that, in making treatment-limiting decisions, doctors who act responsibly, in the way we have described, have adequate protection under existing law.

257. Nor do we think it helpful to attempt a firm distinction between treatment and personal care², implying that the former may be limited and the latter not. The two are part of a continuum, and such boundary as there is between them shifts as practice evolves and particularly as the wider role of nursing develops. This boundary is one which the courts were required to try to define in the case of Tony Bland, and that gave rise to much debate about whether nutrition and hydration, even when given by invasive methods, may ever be regarded as a treatment which in certain circumstances it may be inappropriate to initiate or continue. This question has caused us great difficulty, with some members of the Committee taking one view and some another, and we have not been able to reach a conclusion. But where we are agreed is in judging that the question need not, indeed should not, usually be asked. In the case of Tony Bland, it might well have been decided long before application was made to the court that treatment with antibiotics was inappropriate, given that recovery from the inevitable complications of infection could add nothing to his well-being as a person. We consider that, had Tony Bland's health-care team and family been in agreement on this course, it would have been ethically and practically appropriate for such treatment to have been discontinued. Because of his established pvs there was no duty to strive to preserve his life by medical means. We consider that progressive development and ultimate acceptance of the notion that some treatment is inappropriate should make it unnecessary to

¹ See paragraph 245.

² See paragraphs 60 to 65 above.

consider the withdrawal of nutrition and hydration, except in circumstances where its administration is in itself evidently burdensome to the patient.

PERSISTENT VEGETATIVE STATE

258. The case of Tony Bland made it clear that, quite apart from questions of nutrition and hydration, treatment-limiting decisions are felt to be particularly difficult in respect of patients in pvs¹. This seems to be, at least partly, because of widespread misunderstanding of the condition, confusion over diagnosis and misplaced expectations of improvement. We suggest that the development of a generally accepted definition of the condition would assist both the health-care professions and the wider community, and could in time lead to a code of practice for the management of patients in pvs. A similar process occurred in respect of brain stem death. The issue was initially very controversial and hotly debated². But gradually both medical and lay opinion have evolved to a point where there is now almost total acceptance of a single definition of brain stem death and widespread understanding of its implications and management. We consider that a comparable process of evolving a commonly-accepted definition of pvs and a code of practice relating to management would be helpful. We therefore recommend that the colleges and faculties of all the health-care professions, together with other relevant professional bodies, should seek to establish such a definition. We suggest that it might include the following elements—

- that over a period of not less than 12 months there had been no return of cognitive, behavioural or verbal responses, no purposive motor responses or other evidence of voluntary motor activity
- that the accepted clinical and investigative diagnostic criteria, developed on the basis of those referred to in Appendix 4, were all present
- that the diagnosis of pvs on those criteria should be based on repeated observation by the physician responsible for the care of the patient and should be confirmed by a neurologist of consultant status not previously involved in the case.

“MERCY KILLING”

259. We have considered suggestions that, although deliberate killing should remain a criminal offence, killing to relieve suffering (that is deliberate killing with a merciful motive) should not be murder but that a new offence of “mercy killing” should be created³. At present the offence of murder embraces acts of deliberate killing which vary enormously in their character and which most people would agree vary “in degree of moral guilt”⁴. The significant question however is whether the law could or should make a distinction between them.

260. We consider that it should not. To distinguish between murder and “mercy killing” would be to cross the line which prohibits any intentional killing, a line which we think it essential to preserve. Nor do we believe that “mercy killing” could be adequately defined, since it would involve determining precisely what constituted a compassionate motive. For these reasons we do not recommend the creation of a new offence.

PENALTY FOR MURDER

261. Pressure for a new offence of “mercy killing” arises mainly because of the perceived injustice of the mandatory life sentence for murder⁵. We strongly endorse the recommendation of a previous Select Committee⁶ that the mandatory life sentence should be abolished. This would

¹ See paragraphs 156-162 above.

² See Appendix 5 for a brief discussion of this issue.

³ See paragraphs 127-129 above.

⁴ Report of the Committee on the Penalty for Homicide, Prison Reform Trust, London 1993, page 21.

⁵ See paragraphs 130 to 135 above.

⁶ *Murder and Life Imprisonment*, Report of the Select Committee, Session 1988-89, HL Paper 78-I.

enable the judicial process to take proper account of the circumstances of a case and the motives of the accused. It would avoid the law being brought into disrepute either by the mandatory imposition of a life sentence in respect of an act which was widely thought to be compassionate and (by some) arguably justifiable, or by the inappropriate substitution of lesser charges where it was expected that a jury would not convict for murder because of the mandatory life sentence. It would also give scope for an effective life sentence to be imposed where the circumstances made it appropriate.

ASSISTED SUICIDE

262. As far as assisted suicide is concerned, we see no reason to recommend any change in the law. We identify no circumstances in which assisted suicide should be permitted, nor do we see any reason to distinguish between the act of a doctor or of any other person in this connection.

ADVANCE DIRECTIVES

263. We commend the development of advance directives¹. They enable patients to express in advance their individual preferences and priorities in respect of medical treatment should they subsequently become incompetent. Their preparation can (and indeed should) stimulate discussion of those preferences between doctors and patients. They can assist the health-care team and other carers in making decisions about appropriate treatment in respect of patients who are no longer able to take part in that debate. Advance directives may express refusal of any treatment or procedure which would require the consent of the patient if competent. We emphasise however that they should not contain requests for any unlawful intervention or omission; nor can they require treatment to be given which the health-care team judge is not clinically appropriate.

264. We have given careful consideration to the terms of Lord Allen of Abbeydale's private member's bill, and to the points which he set out in his two memoranda. We have also considered the arguments of other witnesses who advocated legislation on the subject of advance directives. But we conclude that legislation for advance directives generally is unnecessary. Doctors are increasingly recognising their ethical obligation to comply with advance directives. The development of case law is moving in the same direction. We agree with the assessment of the Crown Prosecution Service² and confidently expect that a doctor who acted in accordance with an advance directive, where the clinical circumstances were such as the patient had considered, would not be guilty of negligence or any criminal offence. Adequate protection for doctors exists in terms of the current law and in trends in medical practice. We suggest that it could well be impossible to give advance directives in general greater legal force without depriving patients of the benefit of the doctor's professional expertise and of new treatments and procedures which may have become available since the advance directive was signed. We recognise that it would be possible to specify precisely particular categories of treatment which a patient would find unacceptable in **any** circumstances, such as a blood transfusion in the case of a Jehovah's Witness.

265. Instead of legislation for advance directives generally, we recommend that the colleges and faculties of all the health-care professions should jointly develop a code of practice to guide their members. The BMA's Statement on Advance Directives³ has much to recommend it as a basis for such a code. The informing premise of the code should be that advance directives must be respected as an authoritative statement of the patient's wishes in respect of treatment. Those wishes should be overruled only where there are reasonable grounds to believe that the clinical circumstances which actually prevail are significantly different from those which the patient had anticipated, or that the patient had changed his or her views since the directive was prepared. A directive may also be overruled if it requests treatment which the doctor judges is not clinically indicated, or if it requests any illegal action. There should be a presumption, in the absence of any explicit instruction to the contrary, in favour of all ordinary care and clinically-indicated treatment

¹ See paragraphs 181 to 215 above.

² See paragraph 183 above.

³ Published in April 1992 and printed at PP 33-39.

being given. A doctor who treats a patient in genuine ignorance of the provisions of a directive should not be considered culpable if the treatment proves to have been contrary to the wishes therein expressed, and there should be no expectation that treatment in an emergency should be delayed while enquiry is made about a possible advance directive. Doctors who anticipate having conscientious objections to complying with the directives of their patients should make this clear at an early stage in their preparation, so that patients may transfer to other doctors if they wish.

266. The code of practice should also encourage professionals to disseminate information about advance directives. It should establish procedures for a directive to be lodged by a patient with the general practitioner, who should be required to produce it to any other health-care professional who has care of the patient, for example on the patient's admission to hospital. The existence of an advance directive could be indicated by a card which the patient would carry, and the code should make provision for such a practice.

267. We also recommend that the proposed code of practice should encourage, though not require, regular review and re-endorsement by patients of the provisions of their advance directives. This would not only go some way towards eliminating the danger of a directive becoming out of line both with medical practice and with the patient's current wishes but would also demonstrate the patient's continuing commitment to the directive, which would reinforce its value as a statement of the patient's wishes.

PROXY DECISION-MAKING¹

268. Whilst the idea of the patient-appointed proxy is in many ways attractive, it is vulnerable to the same problems as advanced directives, and indeed to a greater degree. Whilst the intentions of a mature adult may remain tolerably stable for many years, the same cannot be said about the person whom the future patient regards as most suitable to reflect in a sympathetic and sensitive manner the particular mixture of ethical, social, religious and emotional premises which would have determined any choice made by the patient. Personal relationships are not immutable, and the choice of proxy might become out of date within quite a short time. Thus, unless the advanced choice is repeatedly revised, something which (life being what it is) may well not happen, there is a risk that when the time for decision arrives it will fall to be made by someone who has lost the close rapport with the patient that once existed, and who may indeed through changes in relationships be someone whom the patient would no longer wish to represent him or her.

269. Furthermore, the two types of substituted decision-making² are open to objections, both conceptual and practical, which have been widely discussed in the literature. The conceptual difficulties are particularly prominent in relation to surrogates of the second kind, where the appointment is made, not by the patient himself, but on an *ad hoc* basis by an external agency once the question of withholding or withdrawing treatment has arisen. Thus, for example, the appointment of a surrogate to act for a patient who, through mental infirmity, has never been competent to form a reasoned judgment, seems to stretch the concept of patient autonomy to breaking point. This would also be the case if the patient were a carefree young adult, living solely in the present, with no thought for the morrow and no true understanding that life may change for the worse, and having no taste or capacity for addressing the wider and deeper issues raised by grave illness, inability to communicate, destruction of personal dignity and erosion of the quality of life. It may be said with force that it is no more than a fiction to suppose that a surrogate in choosing between life or death is making a choice as the representative of the patient when it is a choice which the patient never had the occasion to contemplate.

270. The practical difficulties of ascertaining what choice the patient would have made if capable of doing so have been widely recognised. Even a thoughtful and articulate person, discussing the question in depth with relatives or peers, may not have foreseen the kind of bodily

¹ See paragraphs 216 to 221 above.

² See paragraph 217 above.

or mental extremity which puts the continuation of life in issue; and in the majority of cases, no such discussions will have taken place, so that the putative intentions of the patient would have to be gleaned from random previous statements, coupled with a general appreciation of the patient's moral and social convictions. It has been asserted that as the sole basis for decision, divorced from wider consideration of "best interest", this type of material is unreliable for three reasons. First, "verbal expressions of preferences lack the indicia of commitment and thoughtfulness attributable to actual choices. Second, because a person's preferences can change radically over time, use of prior statements ignores the possibility that the person may have incorporated revised goals, values, and definitions of personal well-being into the decision he would make. Finally, informal oral statements are likely to be so general as to provide little guidance in concrete treatment decisions¹."

271. The fact that even a decision made by the surrogate in complete good faith may lack objectivity cannot be ignored. As the prolongation of life becomes ever more successful, and more expensive, a surrogate (who may often be either paying the bills or be entitled to benefit from the patient's estate which is being depleted by the bills) cannot be unaware of the financial detriment which prolongation carries in its train - a problem which the patient himself might not have foreseen. Conversely, the psychological pressure on a surrogate who is also a member of the family may cause him or her to insist on the maintenance of life beyond the point at which the patient, if competent, would have wished the struggle to be abandoned. Whilst acknowledging the strong current of opinion in favour of proxy decision-making, for all these reasons we do not favour the more widespread development of such a system. There is however no reason why an advance directive should not contain a request to doctors to consult if practicable with a third party, without the doctors being necessarily bound by that third party's opinion.

PROFESSIONAL RESPONSIBILITY

272. Some people may consider that our conclusions overall give too much weight to the role of accepted medical practice, and that we advocate leaving too much responsibility in the hands of doctors and other members of the health-care team. They may argue that doctors and their colleagues are no better qualified than any other group of people to take ethical decisions about life and death which ultimately have a bearing not only on individual patients but on society as a whole. But no other group of people is better qualified to do so. Doctors and their colleagues are versed in what is medically possible, and are therefore best placed to evaluate the likely outcomes of different courses of action in the very different circumstances of each individual case. By virtue of their vocation, training and professional integrity they may be expected to act with rectitude and compassion.

273. Moreover, health-care professionals are by no means a homogeneous group: they bring to their practice a variety of philosophical and religious views which make it unlikely that any single ethos is likely to dominate accepted practice in a way which might prejudice the interests of an individual patient. In any event, few decisions of the kind which we have discussed are any longer taken by a practitioner acting alone. The increasing emphasis on discussion with the patient or, in the case of an incompetent patient, on consultation with the patient's family or friends, means that the values and priorities of the individual are given proper weight in the decision-making process. This is further reinforced by the growing importance attached to collective decision-making by the health-care team as a whole, and in particular, the greater participation of nurses in the decision-making process. This is another way in which a further point of view, informed by the close, constant contacts which nurses have with the patient or relatives, is involved in deciding appropriate courses of action. The breadth of experience of a hospital chaplain or other spiritual adviser is another resource which may be drawn upon.

¹ Harvard Law Review, Vol. 103 No. 7, May 1990, "Developments - Medical Technology and the Law," page 1650.

HEALTH-CARE RESOURCES

274. Obviously, resources for health-care are not infinite. There are limits to what society is able and willing to afford and rationing of resources has become a fact of life in all developed societies. As medical technology becomes more sophisticated and therefore more expensive, difficult and at times controversial decisions must be made about priorities. An element of inequity is inevitable. The development of new treatments for example is particularly costly, and the very latest options will be available to few patients, though it may be hoped that they will lead the way for others.

275. Nonetheless health-care teams should not be put in a position of having to make such decisions in the course of their day-to-day clinical practice. Their concern must be for the welfare of the individual patient. Decisions about the treatments which society can afford should be made elsewhere than in the hospital ward or the doctor's consulting room, and they should be made on the basis that such treatments as society does wish to fund must be available equally to all who can benefit from them. In particular we would emphasise that treatment-limiting decisions of the kind which we have discussed should depend on the condition of the individual patient and on the appropriateness to that patient of whatever treatment or methods of management are generally available, and should not be determined by considerations of resource availability.

276. Despite the inevitable continuing constraints on health-care resources, the rejection of euthanasia as an option for the individual, in the interest of our wider social good, entails a compelling social responsibility to care adequately for those who are elderly, dying or disabled. Such a responsibility is costly to discharge, but is not one which we can afford to neglect. In this connection therefore we make the following recommendations—

- high-quality palliative care should be made more widely available by improving public support for the existing hospice movement, ensuring that all general practitioners and hospital doctors have access to specialist advice, and providing more support for relevant training at all levels
- research into new and improved methods of pain relief and symptom control should be adequately supported and the results effectively disseminated
- training of health-care professionals should do more to prepare them for the weighty ethical responsibilities which they carry, by giving greater priority to health-care ethics and counselling and communication skills
- more formal and regular consideration of health care ethics at a national level would be helpful
- long-term care of those whose disability or dementia makes them dependent should have special regard to the need to maintain the dignity of the individual to the highest possible degree.

CONCLUSION

277. In conclusion, we wish to thank all those who devoted much time and effort to presenting to us their sincerely held opinions. The task of formulating our opinion in the light of their arguments has been a difficult and demanding one. But in the end we have been able to achieve a consensus, and are unanimous in making this report to the House.

PART 4 SUMMARY OF CONCLUSIONS

278. We recommend that there should be no change in the law to permit euthanasia (para. 237).
279. We strongly endorse the right of the competent patient to refuse consent to any medical treatment (para. 234).
280. If an individual refusal of treatment by a competent patient is overruled by the Court, full reasons should be given (para. 235).
281. We strongly commend the development and growth of palliative care services in hospices, in hospitals and in the community (para. 241).
282. Double effect is not in our view a reason for withholding treatment that would give relief, as long as the doctor acts in accordance with responsible medical practice with the objective of relieving pain or distress, and without the intention to kill (para. 242).
283. Treatment-limiting decisions should be made jointly by all involved in the care of a patient, on the basis that treatment may be judged inappropriate if it will add nothing to the patient's well-being as a person (para. 255).
284. We recommend that a definition of pvs and a code of practice relating to its management should be developed (para. 258).
285. Development and acceptance of the idea that, in certain circumstances, some treatments may be inappropriate and need not be given, should make it unnecessary in future to consider the withdrawal of nutrition and hydration, except where its administration is in itself evidently burdensome to the patient (para. 257).
286. Treatment-limiting decisions should not be determined by considerations of resource availability (para. 275).
287. Rejection of euthanasia as an option for the individual entails a compelling social responsibility to care adequately for those who are elderly, dying or disabled (para. 276).
288. Palliative care should be made more widely available (para. 276).
289. Research into pain relief and symptom control should be adequately supported (para. 276).
290. Training of health-care professionals should prepare them for ethical responsibilities (para. 276).
291. Long-term care of dependent people should have special regard to maintenance of individual dignity (para. 276).
292. We support proposals for a new judicial forum with power to make decisions about medical treatment for incompetent patients (paras. 245, 246).
293. We do not recommend the creation of a new offence of "mercy killing" (para. 260).
294. We strongly endorse the recommendation of a previous Select Committee that the mandatory life sentence for murder should be abolished (para. 261).
295. We recommend no change in the law on assisted suicide (para. 262).
296. We commend the development of advance directives, but conclude that legislation for advance directives generally is unnecessary (paras. 263, 264).
297. We recommend that a code of practice on advance directives should be developed (paras. 265-267).
298. We do not favour the more widespread development of a system of proxy decision-making (para. 271).

APPENDIX 1

Orders of Reference, etc.

Session 1992-93

Die Martis 16° Februarii 1993

Medical Ethics—It was moved by the Lord Privy Seal (Lord Wakeham) that a Select Committee be appointed to consider the ethical, legal and clinical implications of a person's right to withhold consent to life-prolonging treatment, and the position of persons who are no longer able to give or withhold consent; and to consider whether and in what circumstances actions that have as their intention or a likely consequence the shortening of another person's life may be justified on the grounds that they accord with that person's wishes or with that person's best interests; then it was moved by the Lord Stallard as an amendment thereto in line 1, to leave out ("Medical Ethics") and insert ("Euthanasia"); after debate, the amendment was negatived; then it was moved by the Lord Robertson of Oakridge as an amendment thereto in line 7, at end to insert ("and in all the foregoing considerations regard is to be paid to the likely effects of changes in law or medical practice on society as a whole."); on question, tellers for the Not Contents not having been appointed, the amendment was agreed to pursuant to Standing Order 51; then the original motion, as amended, was agreed to.

Die Mercurii 24° Februarii 1993

Medical Ethics—It was moved by the Chairman of Committees, That, as proposed by the Committee of Selection, the following Lords be named of the Select Committee—

| | |
|------------------------------|---|
| L. Colwyn | L. Meston |
| B. Flather | L. Mishcon |
| L. Hampton | L. Mustill |
| B. Jay of Paddington | L. Rawlinson of Ewell |
| B. Llewelyn-Davies of Hastoe | L. Walton of Detchant (<i>Chairman</i>) |
| L. McColl of Dulwich | B. Warnock |
| B. McFarlane of Llandaff | Abp. York |

That the Committee have power to adjourn from place to place;

That the Minutes of Evidence taken before the Committee from time to time be printed and, if the Committee think fit, be delivered out;

That the Committee have power to appoint Specialist Advisers;

That the Committee do meet on Tuesday 9th March at half-past ten o'clock in Committee Room 4B; then it was moved by the Lord Stallard as an amendment thereto, in line 1, to leave out from ("That") to end of line 16 and insert ("the membership and chairmanship of the Select Committee be reconsidered by the Committee of Selection"); after debate, the amendment was (by leave of the House) withdrawn; then the original motion was agreed to.

Die Martis 2° Novembris 1993

Medical Ethics—It was moved by the Chairman of Committees that notwithstanding the prorogation of Parliament, the Select Committee on Medical Ethics shall have power to meet in the next session of Parliament until such time as the House makes further orders of appointment; the motion was agreed to.

Session 1993-94

Die Lunae 22° Novembris 1993

Medical Ethics—It was moved by the Lord Privy Seal (Lord Wakeham) that a Select Committee be appointed to consider

the ethical, legal and clinical implications of a person's right to withhold consent to life-prolonging treatment, and the position of persons who are no longer able to give or withhold consent;

and to consider whether and in what circumstances actions that have as their intention or a likely consequence the shortening of another person's life may be justified on the grounds that they accord with that person's wishes or with that person's best interests;

and in all the foregoing considerations to pay regard to the likely effects of changes in law or medical practice on society as a whole;

the motion was agreed to.

Die Martis 23° Novembris 1993

Medical Ethics—It was moved by the Chairman of Committees that, as proposed by the Committee of Selection, the following Lords be named of the Select Committee:

| | |
|------------------------------|---|
| L. Colwyn | L. Meston |
| B. Flather | L. Mishcon |
| L. Hampton | L. Mustill |
| B. Jay of Paddington | L. Rawlinson of Ewell |
| B. Llewelyn-Davies of Hastoe | L. Walton of Detchant (<i>Chairman</i>) |
| L. McColl of Dulwich | B. Warnock |
| B. McFarlane of Llandaff | Abp. York |

That the Committee have power to adjourn from place to place;

That the Minutes of Evidence taken before the Committee from time to time be printed and, if the Committee think fit, be delivered out;

That the Proceedings of the Select Committee on Medical Ethics in the last session of Parliament be referred to the Committee;

That the Committee have power to appoint Specialist Advisers;

That the Committee do meet this day at a quarter-past four o'clock, in Committee Room 4;

the motion was agreed to.

APPENDIX 2

Letters

In addition to evidence from witnesses listed in Appendix 3, we received letters from 158 individuals or groups. Some were very brief, others longer and closely argued. In most cases the writer clearly expressed an opinion either for or against euthanasia—62 for, 86 against.

For euthanasia

Of those individuals who wrote in favour of euthanasia, 13 identified themselves as doctors and 18 as nurses. Eleven said that they were members of the Voluntary Euthanasia Society, and of those two said that they were writing at the suggestion of the Society. Three specifically identified themselves as Christians, while two further individuals spoke of death as going to meet God.

Four people (one doctor and three nurses) said that euthanasia is practised at present, but furtively, and that it would be preferable that it should be done openly and with regulation. Another doctor wrote of existing hypocrisy and double standards, and another said that it was specious to distinguish between active and passive euthanasia. A nurse said that it was hypocritical to distinguish between euthanasia and withdrawal of treatment, since often the outcome was the same, but withdrawal of treatment could result in longer suffering.

Eighteen people said that their viewpoint had been influenced by witnessing the deaths of family, friends or patients. One wrote of “too many deaths by inches, where release was longed for but long delayed”.

Fourteen people emphasised that it was the fear of indignity, dependence and loss of functions that informed their support for voluntary euthanasia. One of these, herself elderly and disabled, said that indignity and dependence could make individuals feel that the value of their good years was being negated, and that gradually diminishing ability to live a full life could make death desirable. Another, writing of her mother who after a distinguished career suffered severe dementia and was bedridden, said that “the end of my mother’s life was everything that she would least have desired” and that it was an unfitting end to a life of achievement and distinction.

Four people wrote specifically of the importance of autonomy or self-determination. Several said that since society respected the rights of those for whom the value of life was paramount, so it should also respect the rights of those who sought some control over the time and manner of their dying. One lady of 81 years wrote of her wish to arrange to die “holding hands with dear ones”.

Six people wrote that they were themselves suffering from the effects of stroke or from progressive disease and feared continuing their lives in increasingly disabled states. One lady with multiple sclerosis said that she would see euthanasia as a “merciful and God-given gift of release”. Three people mentioned the possibility of suicide as a way out. Another lady with MS wrote of her dilemma:

“It is likely that, at some point in the future, the quality of my life will be reduced to the extent that I no longer wish to live. No matter how good the support that is offered, I believe I have the right to decide that my life is no longer tolerable. It is probable that I will reach this point when I am no longer, due to my illness, able to kill myself. Therefore, with the law in its current state, I am left with two choices. Either I kill myself while I still can, knowing that I am losing an indeterminate period of good quality life or else I rely on those who love me to help, knowing that they are likely to be charged with assisting a suicide. Because I also love them I will probably choose the former. It seems cruel and foolish.”

Two people raised the question of proper use of limited health-care resources, one suggesting that it was wrong for people who wished to die to be kept alive, while others died for lack of renal dialysis. Another person mentioned altruism as a motive for seeking one’s own death, but did not specifically mention financial resources.

Fifteen people said that they had completed advance directives setting out their wishes about medical treatment in the event of their being unable to participate in decision-making. Most of them said that they would wish the status of advance directives to be clarified in law, so that they could have greater confidence that their wishes would be respected.

Six people cited practice in the Netherlands as an example to be followed. Four people emphasised the need for safeguards to ensure that requests for euthanasia were truly voluntary, one suggesting that application should be made to a tribunal in advance of the act so that all relevant circumstances could be considered and other action (such as treatment for depression) be undertaken if necessary. Three people, two of them doctors, mentioned the need for a "conscience clause" for health-care workers who objected to being involved in the practice of euthanasia.

Two people suggested that "do not resuscitate" orders should be the subject of more discussion between patients and professionals. Three people acknowledged the valuable role of hospices, but noted that even in such a setting not all distress could be relieved and that in any case a hospice was not an option which everyone would choose.

Against euthanasia

Of those individuals who expressed views against euthanasia, 19 identified themselves as doctors, four as nurses. Twenty-five identified themselves specifically as Christians, including three priests and three nuns, while another four people spoke of life as a gift from God. There were also three letters from groups of the Sisters of Charity, and a letter from the Wesleyan Reform Union of Churches. We received 16 letters from members of the House of Commons, and two from members of the House of Lords. One letter carried 21 signatures collected in the Wolverhampton area. Another was signed by 13 medical students in Nottingham.

Eleven people likened the debate on euthanasia to that on abortion, and suggested that both undermined society's proper respect for human life. Several also suggested that, like abortion, euthanasia would be hard to regulate. Sixteen letters raised the "slippery slope" argument, that once voluntary euthanasia was permitted involuntary euthanasia would be likely to follow. Five cited practice in the Netherlands in support of this point, while one referred to experience in Nazi Germany.

Seventeen letters suggested that the hospice movement was the answer to calls for euthanasia, and that it was no longer inevitable that death should be a painful or distressing experience. Nine people cautioned that to permit euthanasia would be to undermine the hospice movement and to remove the incentive for progress in care of the dying.

Six people said that euthanasia should not be permitted because of the dangers of misdiagnosis of a patient's condition.

Eight people wrote of the pressure that could be brought to bear on the vulnerable if euthanasia were available. Four suggested that requests for euthanasia were usually really requests for reassurance and support, and were not often persisted with if such support was forthcoming. Two doctors said that requests for euthanasia were in any case very rare. Five people said that rather than consider euthanasia, society should give better support to the disadvantaged: "the moral integrity of a society should mainly be judged by the way it cares for its sick, poor, old, vulnerable members".

Nine people, seven of them health-care professionals, suggested that the trusting relationship between patient and doctor would be undermined if euthanasia were permitted.

Six people, five of them doctors, said that there was no problem with the *status quo*. They had no difficulty with double effect, nor with the "razor's edge" between killing and letting die, although the distinction was subtle. Eight people said that they regarded the provision of nutrition and hydration, by whatever means, as basic care which should never be withdrawn from a patient.

Five people wrote, three citing personal experiences, of the value to the individual and their families of the last days before death, which euthanasia would curtail: "the final days in a terminally ill patient's life can be some of the deepest, noblest and best". One lady wrote that she believed her father had come to know God in the last days before his death, which would not have happened had his earlier requests for euthanasia been complied with.

Nine people expressed opposition to advance directives, in particular because patients might change their minds or their decisions might not be adequately informed. Three people said that they regarded advance directives as a "stalking horse" for euthanasia.

Three people wrote from their personal experience of a family member having sustained severe brain damage after accident or cerebral haemorrhage. In each case medical staff had wished to discontinue active treatment, and in two cases feeding, but the families had objected. Some degree of recovery had been achieved in each case, and the families continued to value the lives of their loved ones. One mother whose son could not communicate or make any purposeful movement, but was cared for and loved at home, said that there was still meaning in his life. She went on—

“it will be a very sad day when this country admits that it is so impoverished, financially and morally, as to have to deny the sanctity of life to some of its people”.

Other views

In ten cases the writer expressed no clear view for or against euthanasia. In three of these letters it was not clear what the writer intended. Another three people, writing in the light of experience of a friend or family member, objected to the strenuous use of medical technology to prolong the lives of people to whom life had become a burden because of disability, age or weakness. One man wrote that he had assisted his wife's suicide when, in the terminal stages of cancer, she had not wished to continue the struggle; he would have preferred her to have medical assistance in her act, to ensure that her death was easy and certain. Three people wrote to express support for the development of advance directives.

APPENDIX 3

*Visit to the Netherlands**4th and 5th October 1993**Present:*

B. Jay of Paddington
L. McColl of Dulwich
B. McFarlane of Llandaff
L. Mishcon
L. Rawlinson of Ewell
L. Walton of Detchant (Chairman)

1. PROGRAMME

The Committee had meetings with the following:

(i) Ministry of Justice—

Mr A Kors, Raadadviseur, Legislation and Public Law.

(A legal counsellor with several years' experience preparing legislation on euthanasia).

(ii) Dutch Physicians' League—

Dr Karel Gunning, President (also President of the World Federation of Doctors who Respect Human Life);

Dr van Rijn, Vice-President;

Dr Droop, Secretary;

Dr Smits, Legal Adviser.

(The Dutch Physicians' League is a grouping of doctors opposed to euthanasia, with a membership of approximately 650).

(iii) Professor P van der Maas, Institute of Public Health, Erasmus University, Rotterdam

(Professor van der Maas was one of the authors of the main survey for the R Emmelink Committee.)

(iv) Ministry of Welfare, Public Health and Culture—

Mr J J F Visser, Deputy Head, Medical Ethics Section;

Dr G van der Wal, Medical Inspector, Medical Inspectorate of Health for North Holland.

(Dr van der Wal was author of another survey which provided material to the R Emmelink Committee).

(v) Royal Dutch Medical Association—

Mrs Lanphen, Vice-President;

Dr R Dillmann, Secretary, Medical Affairs;

Mr Legemaate, Legal Counsellor.

(RDMA is the main professional association for doctors in the Netherlands, with a membership of approximately 25,000, out of a total of approximately 40,000 doctors).

2. SOCIAL BACKGROUND

It was suggested that, paradoxically, Dutch society was adventurous and not easily bound by convention, but at the same time had a strong attachment to tradition. The Calvinist tradition among much of the population was important, and this meant that moral issues were openly and deeply

discussed, to arrive at considered judgments. This had been seen not only in connection with euthanasia but also with drug use, abortion and the age of consent. Where social behaviour was seen to be changing, Dutch culture demanded that there should be public debate of the issues and that a sound ethical position should be established.

Professor van der Maas suggested that the fact that Dutch society valued individual human life very highly made it possible for them to debate euthanasia openly and confidently, and that perhaps with a different background they would not dare to do so.

3. THE LEGAL POSITION

Euthanasia is defined by the Dutch Penal Code as the taking of another person's life at that person's express request. Under Article 293 of the Code it is a criminal offence punishable by a maximum of 12 years' imprisonment. Other types of killing are dealt with by other Articles of the Code (for example on murder and homicide).

In 1984 the Dutch Supreme Court accepted the so-called emergency defence to the offence of euthanasia, finding that a physician's duty to abide by the law may be outweighed by the duty to help a patient who is suffering unbearably. Since then the courts have laid down a number of criteria by which it may be determined whether or not the emergency defence applies in a given case of euthanasia. In summary the criteria are:

- (a) the request for euthanasia must come only from the patient and must be entirely free and voluntary
- (b) the patient's request must be well considered, durable and persistent
- (c) the patient must be experiencing intolerable suffering with no prospect of improvement
- (d) other alternatives to alleviate the patient's suffering must have been considered and found wanting
- (e) euthanasia must be performed by a doctor
- (f) the doctor must consult an independent colleague, before performing euthanasia.

When euthanasia is performed, the doctor is expected to indicate as much on the patient's death certificate. The circumstances surrounding the act are considered by the local public prosecutor who, if the above criteria have been fulfilled, will decide not to prosecute. All such decisions are reviewed on a regular basis by a meeting of the solicitors-general of each of the 5 courts of appeal, and ultimately political responsibility for every decision not to prosecute rests with the Minister of Justice. This filter mechanism was thought to be quite effective: in each of 4 cases currently pending, the local public prosecutor had decided not to prosecute but the decision had been overturned by the meeting of solicitors-general with the approval of the Minister.

In view of the anomalous position which the Supreme Court decisions have created, there have been repeated attempts to legislate on the subject of euthanasia. In 1986 a Bill was introduced to amend the Penal Code so that euthanasia should not be an offence if practised in accordance with criteria which closely corresponded to those developed by case law (summarised above). In 1987 a Bill was introduced which would incorporate criteria for euthanasia into the Act on Medical Practice, though euthanasia would remain an offence under the Penal Code. In 1993 an opposition party introduced a Bill similar to that of 1986. All three Bills failed.

Following the recommendations of the Rummelink Committee, which considered the extent and conduct of the practice of euthanasia in the Netherlands, the present coalition government introduced Bill 22572. This was passed in February 1993 by the Second Chamber of the Dutch parliament and was passed by the First Chamber in November.

Bill 22572 made no amendment to the Penal Code but amended the Burial Act 1955, to specify the reporting procedure which the doctor must follow where euthanasia is performed. Therefore euthanasia remains an offence but the statute established a policy of non-prosecution where the correct procedure is followed and the specified criteria fulfilled.

It was generally agreed that this legislative anomaly was less than satisfactory, but that previous failed attempts showed that a more consistent solution was not politically possible. However it was important that the practice of euthanasia should be regulated. Mr Kors suggested that putting the practice on a legal footing would bring it fully into the open, prompting discussion in the medical profession and more thorough consultation over proposed courses of action. Professor van der Maas agreed that, while completely watertight safeguards against abuse would be impossible to devise, protection of patients

would be greatly strengthened by increased openness and debate. Many general practitioners in the Netherlands were still in single-handed practice, and they in particular needed encouragement to consult adequately. A few doctors in his survey had felt they had in the past made mistakes of judgement in connection with euthanasia, so improved consultation was very desirable. Professor van der Maas also said that there was widespread intuitive support for retaining euthanasia as an offence under the Penal Code, since the general prohibition on killing was important to society.

4. PROSECUTIONS AND DISCIPLINARY PROCEEDINGS

The number of prosecutions of doctors for offences in connection with euthanasia has been very small—4 or fewer in any one year. A recent case was of a doctor who had failed to seek a second opinion before performing euthanasia. Four cases were pending; in two there were doubts that the patient had been terminally ill, in two there were doubts that the patient's request had been explicit and voluntary. Only one doctor had ever been imprisoned for an offence in connection with euthanasia, and he had subsequently been released because of a technical error on the part of the police.

On other occasions doctors who were not prosecuted were subject to disciplinary proceedings by one of the five regional Medical Disciplinary Courts. In some cases this was for a technical failure to conform to the guidelines, which amounted to a breach of the medical ethical code, but not of the law. In other cases doctors were disciplined for promising to perform euthanasia and then failing to do so; in these cases the families had complained since the patients had had an expectation of assistance which they had not then received.

5. PUBLIC OPINION

The RDMA said that a variety of social factors had led to current practice of euthanasia: emancipation of patients in medical decision-making, and increasing openness of doctors in discussing with patients their condition, treatment and prognosis; the increasing importance attached to personal autonomy; the focus of the Dutch churches (though not the Roman Catholic Church) on the moral choices made by the individual.

Both Professor van der Maas and Mr Visser suggested that the main impetus towards practice of euthanasia had come from the medical profession. Mr Kors suggested that the majority of the Dutch people would like euthanasia—with the necessary safeguards—to be made legal. The RDMA had pressed for definitive arrangements to be introduced, to clarify the position of doctors.

The Dutch Physicians' League said that many prospective patients, especially elderly people, feared that they would be subjected to euthanasia against their wishes, or would not receive adequate medical treatment. They said that some patients now insisted on written contracts before consenting to hospitalisation. However Professor van der Maas, Mr Visser and the RDMA all said that this view was based on a single survey which was extremely dubious in its methodology, and the findings of which were far from reliable. None of them thought there was any truth in suggestions that elderly people were afraid of entering hospital and blamed scaremongering by the press. The RDMA said that relations between doctors and patients in the Netherlands were very good, and that far from being afraid, most patients were reassured by the knowledge that euthanasia was available as a last resort.

Dr Gunning suggested that opinion polls which had reported strong support for euthanasia were not reliable since the questions put had been biased, for example "would you prefer to die in pain or to have euthanasia?" He also noted that a patients' association opposed to euthanasia had quickly grown to a membership of over 60,000.

The Dutch Physicians' League attributed what public support there was for euthanasia to clever campaigning by the media and by the Dutch Voluntary Euthanasia Society. Many who supported euthanasia did so after witnessing the painful dying of relatives or friends, but this could be avoided by concentration on improving treatment.

Professor van der Maas said that hitherto the question of availability of resources had not entered the debate, since the health service was adequately funded.

The Dutch Physicians' League however perceived a drive to save money on care of the elderly, demented and comatose. They said that although it was not made explicit the issue of resources was a major factor in the practice of euthanasia.

6. INTERPRETATION OF THE CRITERIA

The Dutch Physicians' League complained that the criteria which doctors were required to fulfil in the practice of euthanasia were not an adequate safeguard for patients. The requirement that the patient was in utmost distress was obviously elastic and open to varying interpretations. The requirement that the patient's condition would not be alleviated by further treatment was open to varying medical judgments and could be the subject of error.

Another weakness they suggested was that the facts of the case were reported only by the doctor who performed the act, who was unlikely to report any circumstance which might open the door to prosecution.

The independence of the second doctor who must be consulted has not been closely defined. Mr Kors said that it would be for the public prosecutor to consider that point in each case. The RDMA said that they were currently developing guidelines for their members as to whom it was appropriate to consult. They strongly rejected the suggestion that a doctor would specifically choose to consult a doctor known to support euthanasia.

7. PALLIATIVE CARE

Palliative care is not included in Dutch undergraduate medical training, but is a compulsory part of vocational training for all medical specialities. The standard of nursing home care (ie care for terminally ill patients) was generally thought to be high, although there was room for improvement. There was also said to be good provision for care of patients dying at home.

Some criticism was expressed of the British hospice movement as speaking only from the Christian view-point, and therefore of being one-sided. Mr Visser also observed that Dame Cicely Saunders had said that she would, if necessary, render patients into a state of pharmaceutical oblivion, but that for many this was not an acceptable condition. People who did not share Dame Cicely's Christian belief might prefer not to die in such a condition, but to choose euthanasia instead.

On the other hand the Dutch Physicians' League said that they were jealous of the UK's record in palliative care. They said that if similar levels of care were available in the Netherlands the perceived need for euthanasia would be diminished. In 1988 a survey had found that over 50 per cent of patients with terminal cancer had their pain inadequately relieved, and that 56 per cent of doctors had inadequate knowledge of pain relief techniques. They suggested that doctors who could not alleviate their patients' pain should not consider euthanasia but should be required to consult a palliative care specialist.

Mr Visser and Dr van der Wal accepted that the availability of euthanasia might act as a partial disincentive to the further development of palliative care in the Netherlands. But they also emphasised that patients who knew that in the last resort their doctors would be prepared to perform euthanasia were better able to go on fighting their disease.

Professor van der Maas said that his survey showed the importance of symptoms other than pain in prompting requests for euthanasia, so that even optimal terminal care would not remove demand altogether. Dr van der Wal also said that pain was the main reason for a request for euthanasia in only very few cases, and that the patient's general outlook was more significant.

8. FEELINGS OF DOCTORS

The Dutch Physician's League said that they were afraid of the effects which the practice of euthanasia had on doctors: they suggested that each time a doctor performed euthanasia he or she would make the decision more readily and quickly. On the other hand the RDMA said that doctors did not enjoy performing euthanasia. Usually the patient had to work hard to convince the doctor that euthanasia was the right choice. Better treatments were gaining currency because doctors actively sought alternatives to euthanasia. Doctors always hoped that the second doctor consulted would suggest an alternative which would cause the patient to withdraw the request. Doctors were particularly alert to identify any depression or coercion which might be influencing the patient.

Professor van der Maas said that his survey had shown that doctors performed euthanasia only reluctantly, because of the emotional demands which it made on them. Indeed, three of the doctors interviewed had volunteered that, because of those demands, they would not again agree to perform

euthanasia for a patient, though they might consider it for a loved one. Most of the doctors interviewed had warmly welcomed the opportunity for open discussion of their experience of euthanasia, and had been very frank. Those doctors who had not reported acts of euthanasia had omitted to do so because of the uncertain consequences: the doctor might not know for many months whether or not prosecution might follow, and patients' relatives had in the past been harshly dealt with by police. However as the position became clearer the notification rate was improving.

The Dutch Physicians' League agreed that most doctors who performed euthanasia did so because they sincerely believed it to be the only solution in the circumstances, but suggested that more widespread knowledge of advanced pain control techniques would show that alternatives were possible.

The RDMA said that doctors could never have a personal financial interest in euthanasia, since they were legally precluded from benefitting from the estate of a patient with whose care they had been involved in the last months of life.

9. CONSCIENTIOUS OBJECTION

A number of people emphasised that Dutch practice did not require doctors to perform euthanasia, but permitted them to do so in certain circumstances. It was said to be generally accepted that any doctor could refuse to be involved in euthanasia, and no pressure was exerted on doctors who did so refuse. There was no suggestion that doctors were coerced to take part if they chose not to.

The RDMA said that patients newly enlisting with a GP practice commonly now ask the doctor's view on euthanasia, and seek to enlist with a doctor who shares their own viewpoint, on whichever side.

Mr Visser said that there had been some suggestions that applicants for nursing posts would not be employed if they expressed conscientious objection to abortion or euthanasia. However the Ministry had no evidence that this was a significant or widespread problem.

10. INCOMPETENT PATIENTS

Mr Kors said that the government held strongly to the position that euthanasia was not possible for incompetent patients. Euthanasia could not be requested by a proxy or in an advance directive—the patient's request must be current.

The RDMA said that other decisions about the treatment of incompetent patients were made after discussion among the health-care team and the family.

APPENDIX 4

The Differential Diagnosis of a Persistent Vegetative State

The American Neurological Association Committee on Ethical Affairs (Ann Neurol 1993, 33, 386) recommend that terms formerly in common use such as "the apallic state or syndrome", "akinetie mutism", "coma vigil", "stupor", "alpha coma", "neocortical death" and "permanent unconsciousness" should be avoided. They suggest that only three terms should be defined clinically, viz "coma", "the locked-in syndrome" and "vegetative state".

Coma has been defined (Churchill's Medical Dictionary; 1989) as "a loss of consciousness from which the patient cannot be aroused" and as (Plum and Posner 1980 - "The Diagnosis of Stupor and Coma", FA Davis, Philadelphia) "a state of unarousable psychologic unresponsiveness in which the subjects lie with eyes closed"

The Locked-in Syndrome (Churchill) is: "a condition in which the subject is conscious and alert but tetraplegic, aphonic and anarthric so that communication is only possible through blinking or voluntary eye movements. It is rare and is the result of a lesion or disease of the brain stem".

The Vegetative State has been defined by the American Medical Association Council on Scientific Affairs (JAMA 1990, 263, 426) as "a condition in which the body cyclically awakens and sleeps, but expresses no behavioural or cerebral metabolic evidence of possessing cognitive function or of being able to respond in a learned manner to external events and stimuli."

It is important to add that complete or partial recovery from a comatose state, whether resulting from head injury or brain disease is possible, indeed common, and there may be no resultant permanent disability, or the latter may be mild or severe, depending upon the duration of the coma and its cause. Some confusion in the literature has resulted from the inappropriate usage adopted by some authors suggesting that coma and vegetative state are interchangeable terms; they certainly are not.

Recovery from the locked-in syndrome is rare and it must be stressed again that such individuals, though incapable of moving their limbs and of speaking, are sentient human beings with full awareness of their surroundings, even if dependent upon artificial ventilation, tube feeding and other life support systems for their survival.

It is also important (Celesia 1993, Neurology 43, 1457; Childs et al Neurology 1993 43, 1465) to distinguish between a vegetative state which is a medical diagnosis that can be made by careful clinical observation (often with the aid of ancillary investigations), and which can be made at an instant in time, whereas a persistent vegetative state (pvs) is defined as "a vegetative state that has continued for at least one month" (ANA Committee on Ethical Affairs').

While the diagnosis of pvs is based essentially on the results of repeated clinical observation, tests such as electroencephalography, the measurement of cerebral evoked potentials, CT scanning and (when available) PET scanning may all be helpful in confirming that the cerebral cortex is irrevocably dead. Misdiagnosis is relatively common on admission to hospital (Childs et al 1993) and Dr Keith Andrews, among others, has shown clearly that some patients admitted to hospital in what was originally regarded as a vegetative state have demonstrated substantial recovery with the return of some useful function after several months or even longer. Nevertheless, significant improvement after 12 months from a pvs diagnosed by an experienced neurologist with the aid of appropriate tests is exceptionally rare.

APPENDIX 5

Brain Stem Death

The age old belief that death was synonymous with the heart stopping has been undermined by the advances of medical technology over the past 30 years. The focus of attention has shifted from the heart to the brain and death has come to be seen more as a process than an event.

Although medical opinion has largely accepted that you can have clinical criteria for diagnosing brain death, there are still controversies surrounding the definition of death both in clinical and in philosophical and ethical terms. There has been some debate in the clinical setting because of differences in practice between the United Kingdom and the United States. In the US the definition of brain death requires the confirmed death of the whole brain as indicated by clinical tests and a flat waveform on the electroencephalogram. In the UK the definition requires clinical evidence confirming death of the brain stem which supports vital organs such as the heart and lungs.

Brain death was first clinically described in 1959 by two French physicians who termed it *coma dépassé*. Due to artificial ventilation techniques this state of deep coma was described by a number of physicians, principally in the United States, over the early 1960s. In 1968 the *ad hoc* committee of the Harvard Medical School set out clinical criteria for diagnosing brain death. Very broadly, brain death was described as a loss of whole brain function. It was seen as important to specify what constituted brain death and how it might be reliably diagnosed not only because of questions of continuing to ventilate the lungs despite the absence of brain function but also because of the implications for the timing of organ transplants¹.

The issue of organ transplantation was specifically considered in a medical conference held in Sydney in 1968. This resulted in the Sydney Declaration which reaffirmed the medical view that death was a process but that brain death could be clinically established and that in cases involving transplants two physicians unrelated to the transplantation procedure should confirm the diagnosis².

The 1970s saw a flurry of research papers on how to establish brain death and the development of new techniques and criteria for diagnosis. In 1976 the Conference of Medical Royal Colleges and their Faculties published a memorandum on the "Diagnosis of brain death". It was seen as following on from the Harvard criteria. The memorandum was to help doctors dealing with patients in a coma on ventilators. It proposed diagnostic criteria which were "accepted as being sufficient to distinguish between those patients who retain the functional capacity to have a chance of even partial recovery from those in whom no such possibility exists". The memorandum stated that brain death could be diagnosed with certainty. The British definition centred on the brain stem function rather than whole brain function³.

In the later 1970s the debate moved on from establishing diagnosis to defining death. The Conference of Medical Royal Colleges and their Faculties published a further memorandum in 1979 which concluded that death was generally a process and that "brain death means that the patient is dead, whether or not the function of some organs, such as a heart beat, is still maintained by artificial means"⁴.

The second memorandum reflected a wider concern among the general public about establishing brain death. This related particularly to the question of transplantation. In Britain a major controversy arose following a BBC Panorama programme in October 1980 which was interpreted as implying that doctors were not using all means available (principally electroencephalograms) to determine brain death. The medical establishment denied that their criteria left anything open to chance. The argument revolved around the difference of diagnostic practice in the United States and in Britain⁵.

Since 1980 there has continued to be broad agreement by the medical profession on brain death as equalling death though the criteria for diagnosis, and the existence of legal definitions of brain death, still vary between countries. Advances in medical technology have continued to test clinical decision-making and have contributed to public concern. The main subjects of controversy have moved from the clinical and diagnostic (when is death), to the philosophical and ethical (what is death)⁶.

¹ C. Pallis, *ABC of Brain Death* (1983), p. 1; C. M. Fisher, "Brain Death - A Review of the Concept" in *Journal of Neuroscience Nursing*, October, 1991, vol. 23, No. 5, pp 330-333.

² C. Pallis, *ibid.* pp 2-3.

³ J. Korein, "The Problem of Brain Death: Development and History" in *Ann NY Acad Sci* 1978, 315, 19-38; "Diagnosis of brain death: statement issued by the honorary secretary of the Conference of Medical Royal Colleges and their Faculties in the United Kingdom on 11th October 1976" in *British Medical Journal*, 1976, 2, 1187-88; C. Pallis *ibid.* pp. 6-8.

⁴ "Diagnosis of death: memorandum issued by the honorary secretary of the Conference of Medical Royal Colleges and their Faculties in the United Kingdom on 15th January 1979" in *British Medical Journal* 1979, 1, 332.

⁵ C. Pallis, *ibid.* preface, p. 32; *The Times*, 14th October 1980, 4g; *The Times*, 24th October 1980, 12g; *The Times*, 28th October 1980, 3a; *The Times*, 14th November 1980, 4a; *The Sunday Times*, 23rd November 1980, 3b; *The Sunday Times*, 30th November 1980, 16c.

⁶ P. McCullagh, *Brain Dead, Brain Absent, Brain Donors: Human subjects or human objects?* (1993).

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